

WHERE CULTURE MEETS GENETICS: EXPLORING LATINAS'  
CAUSAL ATTRIBUTIONS OF BREAST AND COLON CANCER AND  
MENTAL MODELS OF DISEASE INHERITANCE

by  
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## **Abstract:**

**Purpose:** To describe Latina immigrants' causal attributions of breast and colon cancer and explore this group's mental models of disease inheritance.

**Methods:** A qualitative exploratory design comprised of freelist, ranking, and open-ended questions was used to interview 22 Latina immigrant women in Spanish.

Participants were asked separately to freelist causes and risk factors for breast cancer and colon cancer. They were then asked to rank certain risk factors in terms of their role in the development of each cancer. SPSS v.21 was used to conduct cultural consensus analysis (CCA) on the rank orders to identify the presence of a cultural consensus model. Participants were asked semi-structured, open-ended questions regarding general disease inheritance. Interviews were transcribed and subjected to applied thematic analysis using Nvivo 11.3.2.

**Results:** CCA showed no consensus surrounding rank of causes of either breast or colon cancer. "Genetics" and "hereditary factors" ranked first and second on average across participants for both cancers. These were the most salient factors in regard to breast cancer and the second and third most salient factors for colon cancer. Participants were less aware of colon cancer than breast cancer. Significant themes around risk factors included: the role of the psyche in causing cancer, the additive nature of risk factors, natural versus unnatural items, and ways to modify cancer risk. In discussing disease inheritance, participants often discussed the ability to modify a genetic predisposition and expressed uncertainty in their own genetic knowledge. Use of certain genetic terminology appeared to correlate with education level.

**Conclusions:** Participants' causal attributions of breast and colon cancer were similar to those seen in the general public but different from the results of a similar study done 20

years ago with a more homogenous Latina immigrant population. Participants' beliefs about genetics and uncertainty about genetic knowledge were also similar to findings of other studies done in other populations. Healthcare providers need not provide Latina immigrant patients with different information on breast and colon cancer and genetics than they would provide non-Hispanic white patients. Additional education about colon cancer is needed in this population as in the general public.

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## **Chapter 1: Introduction and Background**

### **OBJECTIVE AND SPECIFIC AIMS**

Research to understand the sources of health disparities has acknowledged that in addition to biomedical risk factors, culture plays an important role in differential health outcomes. Consequently, understanding cultural differences that may influence health behavior is key in working towards reducing these disparities. Causal attributions are a key component of individuals' illness perceptions and thus impact health behaviors, which may present as health disparities at a population level. While research has explored non-Hispanic White women's causal attributions of breast cancer, less is known about Latina's beliefs about the causes of breast cancer, and little is known about causal attributions of colon cancer in any population. Understanding Latina's causal attributions of breast and colon cancer may provide insight into the determinants of cancer disparities in this population. Because a subset of both breast and colon cancers result from single gene mutations, which confer an increased risk of developing such cancers, understanding causal attributions in Latina populations is relevant to the field of genetics. This is especially true since Latinas have historically underutilized cancer genetic risk assessment counseling and testing services. As these services become a standard part of general healthcare provision, it will become increasingly important to understand ways in which different cultural groups interact with genetic information. One way this can be done is through investigating culturally informed mental models of disease risk and inheritance. The objective of this exploratory study is to describe the cultural models of Latina immigrants regarding causal attributions of breast and colon cancer as well as to explore this group's mental models of disease inheritance.

**Aim #1:** To identify the main causal attributions of breast and colon cancers among Latina immigrants.

**Aim #2:** To use cultural consensus analysis to identify the presence or absence of shared cultural models of causal attributions for breast and colon cancers among participants.

**Aim #3:** To describe the mental models of disease inheritance held by members of the Latina immigrant population.

## **REVIEW OF THE LITERATURE**

### ***Latinos in the United States***

“Hispanic or Latino” is currently the largest minority group in the United States, constituting 17.6% of the population as of July 2015 according to the U.S. Census Bureau. In Maryland specifically, the 2010 census found 8.3% of the population to be Hispanic or Latino, and as of July 2015, the U.S. Census Bureau estimated that 9.5% of the Maryland population is Hispanic or Latino. Notably, the absolute number of Hispanics or Latinos in Maryland doubled during the period 2000-2010, indicating the high level of growth in this segment of the population (<http://quickfacts.census.gov/qfd/states/240001k.html>).

Although the U.S. government refers to this population as “Hispanic or Latino”, organized community groups generally prefer the term “Latino” as an indication of their ties to Latin America (Penchaszadeh, 2001). Furthermore, this term can be used in either masculine, “Latino”, or feminine, “Latina”, forms, allowing for more succinct writing. Consequently, the terms Latino and Latina will be used throughout the remainder of this text. However, it is necessary to clarify to whom exactly these terms refer. The U.S. Office of Management and Budget (OMB) defines “Hispanic or Latino” as “a person of



Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race (<http://www.census.gov/topics/population/hispanic-origin/about.html>).” For the purposes of this paper, the terms Latino/a will refer to people of Spanish-speaking countries of the Western hemisphere, and Latino/a immigrants will refer to persons born in one of these countries who have since immigrated to the United States. Notably, this working definition excludes people of Spanish or Brazilian nationality or descent, mainly due to the cultural focus of this investigation.

### ***Breast and Colon Cancer in the U.S. Latino Population***

Breast cancer is the most common form of cancer among Latinas (American Cancer Society, 2014). Although their overall rates of breast cancer and breast cancer mortality are lower than in African American or Caucasian populations, Latinas are less likely to be diagnosed with a localized stage of disease and more likely to be diagnosed with distant stage (more advanced) breast cancer. In addition, cancer is the leading cause of death for adult Latinos, and breast cancer, specifically, is the leading cause of death of Latinas (American Cancer Society, 2014). Similarly, colon cancer is the second most commonly diagnosed cancer among both Latino men and women (American Cancer Society, 2014). As with the case of breast cancer, Latinos have lower incidence and mortality rates for colon cancer but are less likely to be diagnosed at a localized stage of disease and more likely to be diagnosed at a distant stage of disease than non-Hispanic whites (American Cancer Society, 2014). This results in colon cancer being the second and third leading causes of cancer death among Latinos and Latinas respectively (American Cancer Society, 2014). Clearly, despite lower relative incidences of these

cancers, breast and colon cancer both represent serious public health concerns for the general Latino population in the United States.

#### INHERITED PREDISPOSITIONS TO BREAST AND COLON CANCER

Interestingly, there are both sporadic and hereditary forms of each of these two types of cancer. The most common of the hereditary cancer syndromes associated with these cancers are Hereditary Breast and Ovarian Cancer Syndrome (HBOCS) and Lynch Syndrome, also known as Hereditary Non-Polyposis Colon Cancer. HBOCS is most often associated with a deleterious variant in one of two genes, *BRCA1* or *BRCA2*, although multiple other genes are also known to confer a predisposition to breast and/or ovarian cancer. This condition is estimated to affect 1 in 800 people in the general population and for women, confers an elevated lifetime risk of developing invasive breast cancer of between 33 and 75% and between a 4 and 51% risk of developing ovarian cancer, depending on which gene is found to have a variant (Schnider, 2012). These risks are in comparison to a woman's population lifetime risk of developing breast cancer of around 12% (<http://www.cancer.gov/types/breast/risk-fact-sheet>) and a lifetime risk of ovarian cancer of 1.3% (<https://seer.cancer.gov/statfacts/html/ovary.html>). Therefore, it can be of great utility for a woman who carries a deleterious *BRCA1* or *BRCA2* variant to understand these risks and consequently consider more aggressive means of primary and secondary cancer prevention.

Multiple studies have shown Latinas with a personal or family history of breast cancer to have comparable if not higher rates of *BRCA1* and *BRCA2* variants in comparison with similar women of other US minority groups and non-Hispanic whites (Weitzel et al., 2013). However, studies indicate that utilization of genetic testing for

hereditary breast cancer variants among Latinas is low (Sussner et al., 2014). This underutilization of genetic testing indicates a form of health disparity at play. According to a recent review, further studies have demonstrated that this lower than expected utilization of genetic testing is not due to a lack of interest on the part of Latinas. Once genetic testing for breast cancer is explained to Latina patients, they tend to be as interested or more interested in testing than women of other ethnicities. Rather this disparity seems to be due to less awareness of genetic testing in this population and reduced likelihood of being referred for genetic testing by their providers (Lynce, Graves, Jandorf, Ricker, & Castro, 2016).

Similar to HBOCS, Lynch syndrome confers an elevated risk of developing colon cancer for those found to have the condition. Specifically, individuals with Lynch syndrome have a 70-80% lifetime risk of colon cancer as compared with a general population risk of approximately 5% (Schnider, 2012; <http://www.cancer.org/cancer/cancerbasics/lifetime-probability-of-developing-or-dying-from-cancer>). Again, due to the efficacy of established screening mechanisms, knowledge of carrying a gene mutation associated with Lynch syndrome can be vital to early detection of colon cancer, leading to better outcomes and reduced mortality. It is not known the extent to which Latinos undergo genetic testing for hereditary colon cancer risk.

#### CANCER HEALTH DISPARITIES

The fact that breast and colon cancers in Latinos are more commonly diagnosed at a more advanced and difficult to treat stage of disease is an example of a cancer health disparity. According to the National Cancer Institute, cancer health disparities are

“adverse differences in cancer incidence, cancer prevalence, morbidity, cancer mortality, cancer survivorship, and burden of cancer or related health conditions that exist among specific population groups in the United States (<http://www.cancer.gov/about-nci/organization/crchd/about-health-disparities>).” Importantly, Kagawa-Singer and her collaborators (2010) cite the fact that various studies have shown that biologic factors are unable to explain the full extent of these cancer health disparities and instead suggest that these disparities are in large part due to invisible characteristics such as culture. Furthermore, these authors propose that cancer health disparities occur at all stages of the cancer care continuum, and these disparities cannot be fully addressed until providers recognize that cancer care is provided within the context of Western European American culture (Kagawa-Singer, Dadia, Yu, & Surbone, 2010). Not only do providers need to recognize this problem but the healthcare system should strive to rectify it by offering care in a socially and culturally equitable way by not only providing care for all regardless of race or culture but also being open to different cultural conceptualizations of health, illness, and well-being (Kagawa-Singer et al., 2010). While genetic services are not specifically addressed by the authors, given the above statistics on lower than expected utilization of genetic services for genetic breast cancer risk testing by Latinas, it can be presumed that such services fall within this disparate continuum of cancer care. Therefore, understanding how cultural issues play a role in creating barriers to hereditary cancer testing for Latinas is integral to the fight against cancer health disparities.

### ***Causal Attributions***

In the health literature, the term “causal attributions” is defined as a person’s beliefs about the cause of an illness or beliefs about causation more generally (Pickett,

Allen, Franklin, & Peters, 2013). The terms “illness attribution”, “causal explanation” “health attribution”, “causal belief”, “etiology”, and “perceived cause” are other terms used to describe the same concept (Kleinman, Eisenberg, & Good, 1978). However, for the sake of clarity, this paper will use the term “causal attribution” to refer to a person’s beliefs about the causes of an actual or possible illness.

Theoretically, causal attributions are situated at the crossroads of a variety of theoretical frameworks and models. Two such models, Howard Leventhal’s common sense model (CSM) of illness representations and Arthur Kleinman’s explanatory models of illness include causal attributions, referred to as “cause” and “etiology” respectively, as one of five components of an individual’s more global understanding of an illness (Kleinman et al., 1978; Pickett et al., 2013). In the CSM, the remaining four dimensions of the illness perception are identity, timeline, consequences, and cure and controllability (Pickett et al., 2013). Together with causal attributions, these dimensions constitute the individual’s illness belief which is formed based on information from the sociocultural environment, authoritative sources, and personal experience of the illness (Pickett et al., 2013). Of importance for the present work is the salient role that culture plays in forming such illness representations (Shiloh, 2006). Similarly, in explanatory models of illness, Kleinman and his collaborators (1978) situate etiology alongside onset of symptoms, pathophysiology, course of illness, and treatment to make up the five components of an individual’s explanatory model. Cultural beliefs are prominent in the development of an explanatory model of illness, with social class, education, occupation, religious affiliation, and past experience with illness and health care also contributing to an individual’s model development (Kleinman et al., 1978). Often explanatory models

influence a patient's help-seeking behavior, selection of pathways to care, adherence to treatment, and satisfaction, and an important role of this framework is in understanding that patient and doctor explanatory models may differ, which can lead to impediments to patient care (Kleinman et al., 1978).

Attribution Theory is another important theoretical framework from which to understand causal attributions. This theory has its origins in educational psychology and refers to the process by which people attempt to explain the causes of an outcome (Dumalaon-Canaria, Hutchinson, Prichard, & Wilson, 2014). Attribution Theory assumes that people spontaneously make attributions and specifically that they do so by seeking and organizing information in order to understand their environment and to resolve ambiguity, especially in negative or threatening situations (Case, Royle, & Scheuerle, 2014). In developing this theory, Bernard Weiner posited that attributions can be classified according to three dimensions, which are locus of control, stability, and controllability (Case et al., 2014; Dumalaon-Canaria et al., 2014). Locus of control refers to whether the cause of the outcome is seen as internal (something that happened within or by the person) or external (circumstances or something within the environment). The stability dimension deals with whether the cause is expected to change over time, and, finally, controllability differentiates between causes that can be modified by the individual or another person and causes that are fixed (Case et al., 2014; Dumalaon-Canaria et al., 2014). Although this theory has traditionally been applied in educational or social psychology, its categorization of causal attributions and the premise that people organize information in ways such as to reduce ambiguity make it useful in application to causal attributions for illnesses, which are often negative or threatening situations (Case

et al., 2014). According to this model then, causal attributions are a useful tool in understanding health behavior because they serve as a filter through which health messages are received and interpreted and ultimately influence whether or not such messages are acted upon (Case et al., 2014).

In combining elements of attribution theory with the health belief model (HBM), Jennifer King (1982) proposes a framework for understanding the contributions of causal attributions to health. King's expanded HBM (1982) incorporates a more explicit understanding of the patient's causal attribution because the simple HBM largely ignores that set of cognitive processes. King developed what she referred to as the attributional approach to health behavior in which illness attributions both precede and directly impact health beliefs in the HBM and then indirectly impact health behavior (King, 1982). In this model, causal explanations, including the dimensions of locus of causality, stability, and controllability, interact with other beliefs about health and illness and ultimately impact health behavior. King went on to test the model in a prospective study using attendance at blood pressure screening as the health behavior outcome. She found that adding illness attributions and causal explanations to health beliefs significantly increased the ability to predict which patients would actually attend the screening event. Strikingly, when analyzed separately from health beliefs, causal explanations alone were strong, significant predictors of attendance at screening (King, 1982). Clearly, causal explanations or causal attributions of an illness play an important role in intended and actual health behavior, making them an important area of study for better understanding individual health behaviors including behaviors which may lead to health disparities.

Importantly, work in the area of causal attributions for breast cancer has found that attributions can differ significantly depending on whether or not an individual is affected with breast cancer. A study conducted in Western Australia of 1,109 women with breast cancer diagnosed in the previous six months and 1,633 age-group matched women randomly selected used the risk perception questionnaire and one of two open-ended questions to elicit causal attributions from these women (Thomson et al., 2014). Women affected with breast cancer were asked what they believe had caused their breast cancer while unaffected women were asked what they think causes breast cancer in general. Affected women more commonly cited mental or emotional factors as causing their breast cancer, while 78% of unaffected women attributed breast cancer to familial factors such as genetics (Thomson et al., 2014). This research highlights an important consideration in studying causal attributions, which is that the attributions of affected and unaffected individuals may differ significantly.

### ***Mental Models of Disease Inheritance***

In cognitive psychology, mental models are theoretical constructs surrounding the way in which an individual's knowledge of facts is organized. Mental model theory is concerned with the way in which individuals use naïve theories to understand the world (Henderson & Maguire, 2000). This theory also outlines four important properties of mental models. A mental model is a person's causal understanding of a physical system, can simulate the behavior of a physical system, may overlap with other mental models held by the same individual and provides a framework with which people act in accordance (Henderson & Maguire, 2000).



In her theoretical review of illness representations, self-regulation and genetic counseling, Shiloh (2006), notes that the literature on causal attributions of illness has shown that such attributions commonly include beliefs about inheritance, and that individuals generally acknowledge genetics as a cause of illness. However, what genetics or inheritance mean to people may vary (Shiloh, 2006). The meanings attached to genetic causes require further exploration in order to understand how individuals conceptualize inheritance and how these conceptualizations may impact health behavior. Henderson and Maguire (2000) explored such lay mental models of disease inheritance among first year undergraduate volunteers at a Welsh university using open-ended survey questions. The authors describe three mental models of disease inheritance in this group, which they termed the Constitutional, Mendelian, and Molecular Models (Henderson & Maguire, 2000). These models roughly correspond to three phases in the historical development of genetic understanding, with the Molecular Model most resembling the contemporary scientific understanding of genetics. Nevertheless, these models were not judged as better or worse than each other. Instead each is seen as representing a way in which an individual may understand disease inheritance. As mentioned above, an individual may hold overlapping and even contradictory mental models at the same time, and, in fact, Henderson and Maguire found evidence of various individuals ascribing to some combination of the three models. Using the three models, the authors predict what types of genetic or disease information it would be easiest and most difficult for an individual to comprehend (Henderson & Maguire, 2000).

Since Henderson and Maguire's (2000) work, several other studies have explored lay people's beliefs about inheritance. These studies have drawn from mental model

theory in differing degrees and have not necessarily delineated specific models as Henderson and Maguire did, but they still have sought to explore similar concepts regarding how the lay public conceptualizes genetics and inheritance. So far, all of these studies have used qualitative methods to explore this area, and several overarching themes have come out of these studies. To begin, one study of 62 adults between the ages of 22 and 80 (20 African American and 42 Caucasian) from across the US found that even though individuals could discuss genetics and provide examples of what they believed to be genetic conditions or traits in their families, when asked to explain what it means to say that something is “genetic” these same participants often struggled to respond (Lanie et al., 2004). Similarly, a significant proportion were unsure or misinformed as to the location of genes in the body. While 34% did say that genes are present in every cell in the body, 24% stated that genes are located in the brain and others simply were unsure. This study concluded that many of the participants had at least rudimentary knowledge of genetics but that many also had various misconceptions as viewed from the perspective of Mendelian genetics. The authors suggest that these misconceptions may limit individuals’ ability to grasp more complex genetic concepts and may negatively impact medical practice and patient care. They also note that the most challenging group of individuals would be those who are unaware of their lack of accurate genetic understanding. Despite the existence of misconceptions on the specifics of genetics, other studies have shown that individuals generally endorse the interaction between genes and environment and recognize the importance of addressing both factors and their interplay in combating public health problems (Goldenberg et al., 2013). As might be inferred from the belief in the interaction between genes and environment,

studies have also shown that genetic fatalism is less prevalent than the medical community may fear (Bates, Templeton, Achter, Harris, & Condit, 2003).

Of particular interest to the present study is the finding of cultural or racial differences in beliefs about inheritance. A study using 13 focus groups (7 with individuals identifying as African American and 6 with individuals identifying as European-American) of 108 individuals in Georgia asked participants what the phrase “a gene for heart disease” would mean in various contexts (Bates et al., 2003). Among these contexts, the researchers explored what this would mean for participants in regard to the level of determinism this gene would play in health and also what the health consequences of having such a gene would be. The investigators found that there were racial differences with African Americans perceiving a higher risk than non-Hispanic Whites on the basis of “a gene for heart disease” and also being more likely to perceive the consequences of such a gene as being death or premature death. Another study of 61 British-Pakistani families referred to a UK genetics clinic, identified beliefs about genetics that were very culturally informed (Shaw & Hurst, 2008). Nearly all of the participants felt that mainstream culture in the UK frowned upon first-cousin marriages and that the medical culture implied this was a cause of disease. However, many of these respondents did not see how this could cause disease since their ancestors had been practicing cousin marriage for centuries. Nevertheless, this informed participants’ beliefs about what “genetics” is, often referring to the amount of “genetics” in their family as based on the level of consanguinity. Further informing this model was the fact that most participants saw the father as providing all or most of the genetic material for a child and thus individuals related through the father or male relatives were seen as more related and

having more “genetics” between them than individuals related through maternal lineages (Shaw & Hurst, 2008). Finally, a study of 77 African American and European American individuals divided into 16 focus groups which were separated by race and gender, looked at participants’ perceptions of the influence of genes, environment, social factors, and personal behaviors on health, physical characteristics, abilities, and talents (Parrott, Silk, & Condit, 2003). The researchers found evidence of differing beliefs by race and gender. Specifically, males of both races indicated less genetic influence on height than females did and African American women perceived a greater role of genes in breast cancer than European American women (Parrott et al., 2003). While the methods and small sample sizes preclude these studies from identifying causation, these studies provide evidence of the ways in which race, culture, and gender may inform mental models of disease inheritance.

The connection between mental models of disease inheritance and the study of causal attributions is clear, given that providing causal understanding is one of the four properties of mental models according to mental model theory. Furthermore, these mental models can provide the link between causal attributions and one’s behavior since another property of mental models is that individuals act in accordance with their models. The present study seeks to add to our understanding by studying mental models of disease inheritance in the Latina immigrant population. This exploration will provide greater insight into how Latinas conceive of genetics and disease inheritance and propose ways in which mental models of disease inheritance held by Latinas could influence behavior such as the utilization of genetic testing.

### ***Culture and Cultural Consensus Theory***

As mentioned above, culture is specifically mentioned as playing a role in the development of both explanatory models and illness representations as well as in influencing health disparities. Furthermore, research has demonstrated cultural and ethnic variations in causal attributions (Case et al., 2014; Chavez, Hubbell, McMullin, & Martinez, 1995). However, it is important to clarify what is meant by ‘culture’.

Unfortunately, this concept may be one of the vaguest and most poorly defined in the academic literature. In fact, Unger and Schwartz (2012) mention that the precise definition of culture has been debated for centuries. Nonetheless, many definitions have been proposed, including “a shared set of meanings and ideas held by a group of people” (Unger & Schwartz, 2012) and “the blueprint or guiding framework behind a population group's conscious and unconscious actions, or the “toolkit” for living life, solving problems, and informing decisions...a shared way of being and interacting” (Kagawa Singer, 2012). From these definitions, one can see the salient idea of culture involving shared meanings or knowledge within a group of people.

Cultural consensus theory (CCT) is a collection of analytic techniques and mathematical models created as a way to approach culture and ethnography objectively as a way of more clearly delineating what is meant by culture (Romney, Weller, & Batchelder, 1986). The basis for CCT lies in two main concepts. First, knowledge regarding a cultural domain is spread throughout a cultural group but is not necessarily spread evenly, meaning that some people will have greater knowledge of certain domains than others do. Here it is important to define what is meant by domain. A domain is “an organized set of words, concepts, or sentences, all on the same level of contrast, that

jointly refer to a single conceptual sphere” (Weller & Romney, 1988). Essentially, a domain is a topic or area of understanding. The second important concept for CCT is that it has been shown in test-retest studies that within-informant agreement (an individual’s propensity for giving the same answer to the same question posed on multiple occasions) is a great predictor of between-informant agreement (the likelihood that one individual’s answer is the same as that of another individual). Greater within-informant agreement is seen as a sign of greater knowledge of a domain as the individual is confident in their answer and does not change that answer over time. CCT proposes that if within-informant agreement predicts between-informant agreement, then the opposite should also be true. Consequently, those individuals who most agree with each other are determined to have greater knowledge of the domain and therefore, to be more reliable informants on that domain (Romney et al., 1986).

Using this theoretical basis, CCT is used to estimate the culturally correct answers to a set of questions and simultaneously estimate each respondent’s level of competence in answering these questions when the “correct” answers are originally unknown. This set of culturally correct answers then forms a cultural model surrounding the given domain and each individual’s level of agreement with the model is referred to as his or her level of cultural competence (Romney et al., 1986; Weller, 2007). In this case, competence does not refer to one’s capability or skill but rather to their expertise with regard to the specific cultural understanding. Informants whose responses are less aligned with others in the group are not judged as ‘wrong’. The interpretation is that they do not have as much knowledge of the specified cultural domain or, in fact, ascribe to a different way of viewing this domain from most other members of the group.

This method of analysis allows the researcher to ascertain whether or not a cultural consensus model surrounding a particular domain even exists, based on the general level of agreement across similar respondents (Romney et al., 1986; Weller, 2007). If a consensus model is not found to exist, one of the assumptions of the model is violated, and the researcher learns that this particular domain is not culturally defined within the cultural group of interest (Romney et al., 1986). Since its creation in the 1980s, CCT has been successfully applied to a variety of cultural domains across a variety of cultural groups. A few of these diverse applications have included understanding conceptualization of folk illnesses (Weller et al., 2014) and risk factors for breast and cervical cancer (Chavez et al., 1995).

It is important to note that while one cultural group may have a consensus model in regard to one domain of knowledge or beliefs, they may not share a single model in regard to another domain. In fact, one study using CCT found that Latina immigrants shared a cultural model of risk factors for breast cancer but not for cervical cancer (Chavez et al., 1995). Similarly, although one cultural group shares a model regarding a certain topic, this does not imply that every cultural group must share a model on that particular topic in order to be defined as a group. In the same paper mentioned above, women of Mexican ancestry born in the United States did share a cultural model of risk factors for cervical cancer but Latina immigrants' lack of such a model did not call into question the cultural definition of that group (Chavez et al., 1995). From the understanding of the above points, it follows that presence or absence of cultural models around a specific domain says more about the relationship between the culture and that

domain than it does about the affinity of the cultural group. Furthermore, these models, like all aspects of culture, are not static and can change over time (Kagawa Singer, 2012).

### ***Latinos as a Cultural Group***

Despite the fact that our working definition of Latino includes people of various national origins, this population has been shown to meet the definition of a cultural group as put forth by Unger and Schwartz (2012): a group “of people who hold similar values, beliefs about acceptable behavior and ideas about what it means to be a member of the culture.” Penchaszadeh (2001) supports the argument for Latinos sharing a common culture by noting that in spite of the diversity among Latinos, this group shares many aspects of a common identity. He attributes much of this shared identity to the use of a common language and in many cases a shared social history characterized by Spanish colonization, powerful religious influences, poverty, and lower levels of education (Penchaszadeh, 2001). Furthermore, in their work in elucidating cultural consensus explanatory models for breast and cervical cancer among Mexican immigrant women, Salvadoran immigrant women, Chicanas, Anglo women, and physicians, Chavez and his collaborators (1995) found that Mexican and Salvadoran immigrant women (together referred to as Latina immigrants) shared one cultural model of perceived risk factors for breast cancer. Meanwhile, this model held by Latina immigrants could not be reconciled into a single model with that of Chicanas (defined as U.S.-born women of Mexican ancestry) (Chavez et al., 1995). In other studies done with a group of Puerto Ricans in Connecticut, Mexican-Americans in Texas, Mexicans in Guadalajara, and rural Guatemalans, it was found that despite their geographic and demographic differences, they shared common cultural models of folk illnesses (Weller et al., 2014). These



findings support the idea that Latinos can form part of a single cultural group despite differences in country of origin, and specifically, there is evidence that they share common cultural models of causal attributions in regard to some cancers.

Furthermore, the paper by Chavez et al. (1995) suggested that not only do Latina immigrants share a cultural consensus model in regard to causes of breast cancer, but this model is distinct from those models held by Chicanas, Anglo women, and physicians, indicating that understanding the differences in Latina causal models may provide insight into better understanding health disparities. Another study of differences in causal attributions between ethnic groups, applied the concepts of Attribution Theory to understanding women's causal attributions for birth defects. Using analysis of open-text interviews with 2,672 control mothers in the National Birth Defects Prevention Study who gave birth between 1997-2005, the authors were able to parse out differences among racial and ethnic groups. Interestingly, the authors found that Hispanic women's responses were statistically different from those of non-Hispanic white women in 18 of 52 identified themes (Case et al., 2014). In another study of 439 unaffected women in the general population in the U.S using an 18-item causal attribution scale, Hispanic women were found to be significantly more likely to endorse stress and one's emotional state as causes of colon cancer than non-Hispanic white women (Wang, Miller, Eggleston, Hay, & Weinberg, 2010). As shown here, there is evidence that causal attributions of Latinas differ from those of non-Hispanic Whites in important ways.

### ***Significance of the Current Study***

This study proposes to explore the causal attributions of breast and colon cancers as well as mental models of disease inheritance held by immigrant Latinas in the U.S.

The proposed study adds significantly to the academic literature on these topics. Only minimal investigation into causal attributions of breast cancer and even less research into causal attributions of colon cancer or mental models of disease inheritance has been done in this rapidly growing segment of the United States' population, facing serious cancer health disparities. As culture is recognized to play a role in health disparities, cultural analysis will be used in assessing these domains.

In the case of breast and colon cancers, causal attributions may influence general health behaviors such as smoking or exercise as well as cancer-specific health behaviors such as following recommended screening regimens for early detection of cancer. In regard to genetic attributions specifically, causal attributions serve as the filter through which an individual receives any health message (Case et al., 2014), including a referral to genetic counseling for assessment of one's risk of having a hereditary cancer syndrome. Whether or not an individual ascribes to a genetic causal attribution at all would be expected to play a role in practicing this behavior. However, according to mental model theory, the way in which the individual conceptualizes that genetic causal attribution will further influence whether or not the individual acts upon the referral for genetic counseling (Henderson & Maguire, 2000). Genetic risk information provided through genetic counseling or a primary care doctor does not override an individual's pre-existing mental models but rather is interpreted by the patient and assimilated into his or her previously existing mental model of disease causation and inheritance (Shiloh, 2006). Consequently, better understanding of the cognitions involved in acceptance or rejection of a referral for genetic counseling or testing may provide insight into determinants of utilization of these health behaviors. In the case of hereditary cancer,

understanding the mental models upon which Latinas might choose to refuse hereditary cancer genetic counseling or testing, can illuminate a reason for cancer health disparities in regard to breast and colon cancer for the Latino population and consequently suggest interventions to reduce these disparities.

## **Chapter 2 - Methods**

### ***Study Design***

This study employed a qualitative, exploratory study design incorporating both systematic data collection methods and semi-structured interviews. Data was collected systematically via freelist and rank-ordering of possible causes of breast and colon cancer. Open-ended questions were subsequently used in an interview to collect qualitative data surrounding those freelisted and ranked items. Further open-ended interview questions were used to collect information about participants' mental models of disease inheritance. The combination of these various techniques allowed for direct comparison and aggregation of data across participants as well as flexibility and in-depth understanding.

### ***Study Sample***

A sample of 22 Latinas over the age of 18 were interviewed for this study. Eligible study participants were women over the age of 18 who self-identified as Latina, were currently living in the United States, had been born in Latin America, spoke Spanish, and were able to meet for an in-person interview in the Baltimore-Washington region. Individuals with a personal history of breast, ovarian, or colon cancer were excluded from the study since there is evidence of differing causal attributions between individuals affected or unaffected with a condition (Thomson et al., 2014) and because the goal of this study was to capture beliefs of unaffected individuals. There was no exclusion based on family history of cancer. Finally, members of the research and medical staff at the NIH were excluded from participation since the purpose of the study was to identify and explore lay models of causation of cancer and disease inheritance. After the first six

interviews, an additional screening question regarding highest level of education was added. This was to allow for purposive sampling based on participants' level of education since each of the first six participants had the equivalent of a bachelor's or graduate degree. The researchers wanted to increase the educational diversity of the sample because this study sought a broadly diverse group of Latina immigrants in all areas: age, country of origin, time in the US, and education level. Furthermore, only 12% of immigrant Latinos in the US hold a bachelor's degree or higher (Ryan & Bauman, 2016), so such a highly educated sample would be very unrepresentative of the general US Latina immigrant population.

Participants were recruited from the Baltimore-Washington area via the National Institutes of Health (NIH) Clinical Research Volunteers Program (CRVP), ResearchMatch, and other existing research protocols at the NIH Clinical Center. The investigator (KF) requested a spreadsheet of all female volunteers self-identifying as Hispanic/Latina, over age 18, in Washington DC, Maryland, and northern Virginia who had registered with the NIH CRVP from January 2014 to August 2016. The investigator called and/or e-mailed individuals included on this list, explained the research project, and assessed interest in participation. Concurrently, the investigator used the ResearchMatch database to send an e-mail message to women over age 18 who self-identified as Hispanic/Latina within 50 miles of the NIH Clinical Center. Interested individuals had the option of clicking a link to allow the researcher to contact them. This automatically provided the investigator with contact information for these individuals. She was then able to call and/or e-mail them. Finally, in order to increase the diversity of the sample, recruitment was conducted through existing protocols at the NIH Clinical

Center. In this case, the lead investigator explained the research project and eligibility criteria to a qualified researcher of the collaborating protocol who recruited eligible individuals to the study. Each participant was offered a \$20 gift card for each interview in which she participated.

### ***Procedures***

The lead investigator (KF) carried out all recruitment, screening, and interview procedures. Upon initial contact with the investigator, participants were asked a series of questions to determine their eligibility for the study based on the eligibility criteria described above. Once eligibility and desire to participate were confirmed, the participant and investigator would find a mutually agreeable time and location for the in-person interview. Interviews were conducted in reserved rooms at local public libraries, an interview room at the NIH, or clinic rooms at the NIH Clinical Center.

Prior to recruitment, the study instruments (Appendices A and B) were developed based on the existing literature and the aims of the study. (See below for a more in-depth description of these instruments.) The initial study questions and interview guide were tested in three pilot interviews with women meeting all eligibility criteria but recruited from a local Latino health center. These pilot interviews were used to assess the clarity of interview questions, incorporate additional questions, assess the ease of completing the interview, and estimate the time needed to complete the interview. The interview guide and study procedures were modified based on pilot interviews.

All interviews were conducted in Spanish. At the start of each interview, participants were given a copy of the informed consent document in either Spanish or English, according to participant preference, and the interviewer reviewed the form and

answered any questions. The first 10 participants were asked to complete a Stage I interview in which participants provided demographic information and completed a measure of acculturation as well as providing personal and family cancer history and listing all the causes or perceived risk factors for breast and colon cancer. The order in which each cancer was addressed was counterbalanced so as to minimize any bias based on the order in which each cancer was presented. In order to capture the limits of these domains within the 10 Stage I interviews, after participants reached the end of their ability to freelist causes or risk factors, the interviewer provided various categories of risk factors (i.e. lifestyle, environment, demographic factors) and gave additional time to consider in case these categories prompted the listing of additional causes or risk factors. This process was developed after pilot interviews provided few freelisted causes and risk factors for each cancer and was included in an attempt to capture as much of the breadth of the domains as possible in 10 interviews.

After completion of the 10 Stage 1 interviews, freelisted responses were analyzed for similar perceived causes and risk factors or those that referred to the same idea, and these were collapsed into one item using the most representative wording. Items that were freelisted by three or more participants following either the initial prompt or the category prompts were identified for inclusion in the ranking task.

After identifying this initial list of items, the researchers decided to include in the ranking task some additional causes/risk factors of breast and colon cancer that were not mentioned or that were mentioned by fewer than three participants in the Stage I interviews. This is a common technique used in freelisting and ranking in order to allow participants the opportunity to engage with items that were not freelisted (Weller &

Romney, 1988). In our study, this helped elucidate whether participants did not consider these items to be significant in causing the cancers addressed or whether they simply did not occur to participants when freelisting. These additional items were related to the biomedical model of causes of each cancer or were found to be salient items in a previous study using similar methods (Chavez et al., 1995). See tables 4 and 5 for a complete list of items included for the ranking task as well as differentiation of those identified through freelisting and those included by the researchers.

Following the determination of the final set of causes or risk factors for each cancer of interest, these items were printed on individual cards for use in Stage II interviews. In Stage II interviews, participants were asked to provide the same demographic information and complete the same measure of acculturation as above as well as describe any personal or family history of cancer. Similarly, they were asked to freelist causes/risk factors of breast and colon cancer and these freelist responses were recorded for subsequent salience analyses, even though some of these items may not have been included for the ranking task. Since freelisting was done in these interviews as a means of comparing freelists across the whole sample and less as a way of defining the bounds of the domains of causes of breast and colon cancer, the use of category prompts was omitted from Stage II interviews. Participants had an initial time to think of and list all the causes and risk factors they could think of but were not given additional category prompts.

Next, participants were asked to rank the cards created above in order from most important to least important in terms of causing one of the cancer types. The order of ranking each cancer was counterbalanced similar to the process in the freelisting task.



The interviewer asked the participants closed and open questions regarding the rank they produced in order to verify that the task had been completed correctly and to gather qualitative insight into the participant's causal attributions. The interview concluded with semi-structured questions exploring participants' mental models of disease inheritance.

Participants from Stage I interviews were eligible to take part in Stage II interviews and nine of the ten Stage I participants completed Stage II interviews as well. These participants did not repeat demographic information, cancer history, the acculturation measure or freelisting but started the Stage II interview with the ranking task.

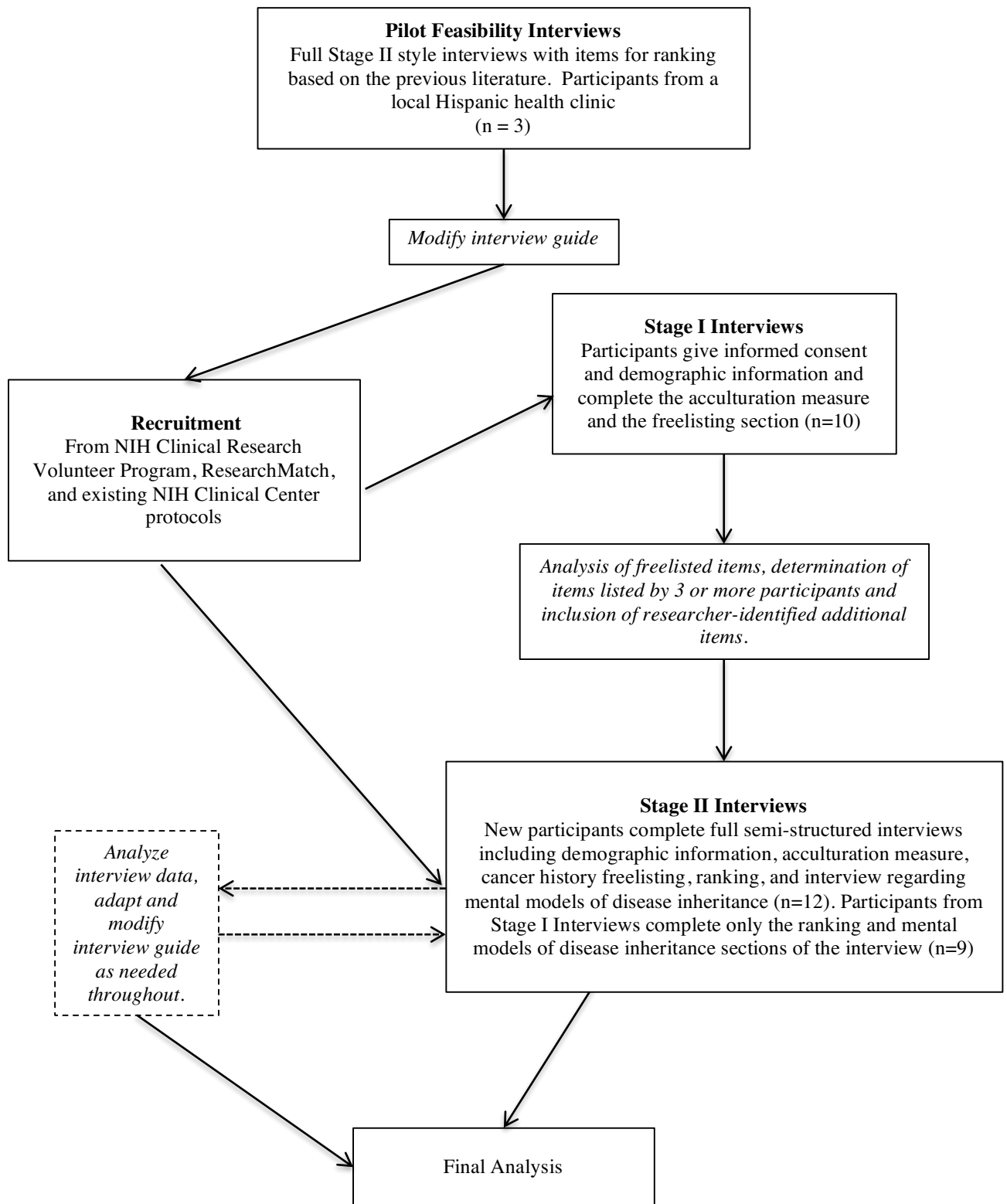
Post-interview, the interviewer immediately filled out a summary sheet (see **Appendix C**) to capture initial impressions. Any unanticipated themes or information were noted for analysis and some were used as probes in future interviews.

Stage I interviews ranged from 21 to 52 minutes and averaged 33 minutes. Stage II interviews ranged from 31 to 72 minutes and averaged 51 minutes.

At the conclusion of the Stage II interview, participants were given two informational pamphlets, one regarding breast cancer and one regarding colon cancer. These pamphlets covered known risk factors for breast and colon cancer as well as screening measures to mitigate these risks and information on who to contact to have these screening procedures or to address any concerns about their personal risk of cancer. (See **Appendix D** for the complete text of these resources).

A flow-chart of the study procedures was as follows:

## Study Overview



### *Study Instruments*

All study instruments were administered in Spanish.

#### DEMOGRAPHIC QUESTIONNAIRE AND ACCULTURATION MEASUREMENT

Participants completed a demographic information sheet containing questions regarding the participant's country of birth, age, age at immigration to the US, years lived in the US, highest level of education completed, and any other languages spoken. This sheet also contained four questions on language use, which comprise the shortened version of the Short Acculturation Scale for Hispanics (SASH) (Marín, Sabogal, Marín, Otero-Sabogal, & Perez-Stable, 1987). This scale has been validated for use in various Hispanic populations and asks participants to choose the best descriptor of their language use in various contexts on a scale of 1 to 5 ranging from "Only Spanish" to "Only English" (Marín et al., 1987).

Both the demographic questions and the SASH were presented on a printed page. Participants had the option of writing answers or having the interviewer go through the sheet with them verbally. See **Appendix A** for a complete interview guide and **Appendix B** for the demographic/acculturation questionnaire.

#### CANCER HISTORY

Participants were asked about their personal and family history of any cancer. For relatives with cancer, individuals were asked about the type of cancer, the approximate age of the relative at diagnosis, the approximate age of the participant at the time the relative was diagnosed, and the outcome of the cancer such as cure, remission, or death. Any additional details shared by the participant during the interview such as closeness of

the relationship or physical location during the time of cancer (i.e. participant in the US and relative in the country of origin) were noted in order to inform analysis.

#### FREELISTING

Each participant was asked to list all the items they could think of that would cause or increase the risk that an individual would develop breast cancer and colon cancer.

Each cancer was discussed separately. In Stage I interviews only, participants were then given category prompts in order to elicit any items the participant may not have thought of originally. These category prompts were the same for each cancer, were presented in the same order for each interview and were: lifestyle, environment/exposures, biological or medical factors, things that one consumes, having children, things that can happen to the body, psychological factors, and demographic factors.

#### RANKING

In this section of the interview, participants were initially provided with 10 cards each with a printed word or phrase referring to a cause or risk factor for developing either breast cancer or colon cancer. Participants were asked to rank these cards in order from the item playing the greatest role in the development of said cancer to that playing the smallest role in the development of said cancer. After ranking the initial ten cards, participants were given three to four more cards at a time to insert in their ranking until all the cards had been included in the order. This method was developed after pilot interviews in which participants struggled to rank order a large number of items at one time. This procedure was then repeated with the cards containing causes or risk factors for the other type of cancer. There were a total of 28 items for ranking in regard to breast cancer and 25 items for ranking in regard to colon cancer.

The interviewer then asked participants closed questions about their ranking such as whether one item ranked above another is in fact more important in causing the relevant cancer in their opinion. This was done to verify that the participant understood and correctly completed the task, and participants were given the opportunity to make changes if desired. Each participant's final rank order was recorded. Open-ended questions surrounding how the rank order was determined and why the most and least important factors were in their respective positions were used to gather qualitative insight into the participant's causal attributions. This section of the interview was semi-structured, and the interviewer used additional questions and probes as appropriate to delve deeper into certain rank items that were of particular significance to the aims of this study or which presented themselves as providing important insight into the beliefs of this population based on previous interviews. This reflected the iterative nature of data collection in which the interviewer used data gleaned from prior interviews to guide her further probing in later interviews.

Of note, the ranking section of one interview was modified in order to accommodate a participant who was unable to read in Spanish. Consequently, the ranking task had to be done verbally and was done using the *quicksort* method (Weller & Romney, 1988). In this method, a random card is first chosen to serve as a "standard" and each other item is compared to this item until there are two piles, those that were judged to be above the standard and those that were below. This process is then repeated with each of the resulting two piles and so on until a complete rank order is achieved.

## MENTAL MODELS OF DISEASE INHERITANCE

After freelist and ranking, the interview moved on to exploring mental models of disease inheritance. In this section, the interviewer began by asking the participant to mention everything that came to mind when hearing the word ‘genetics.’ After that task, the interviewer continued with questions about how the participant thought genes influence health and other open-ended questions regarding the participant’s experience with and beliefs about disease inheritance. This portion of the interview was semi-structured and allowed for exploration of additional themes. These areas of exploration included: types of diseases that are inherited, how inheritance of disease occurs, whether the participant feels there are inherited diseases in her family, and the perceived preventability or controllability of inherited disease. Please see **Appendix A** for a full description of the interview guide.

### *Analysis*

Freelist data from participants was analyzed using Microsoft Excel for Mac 2011 and 2016 and the Free-list Analysis under Microsoft Excel (FLAME) v1.1 add in for Excel (Pennec, Wencelius, Garine, Raimond & Bohbot, 2012). This is an Excel macro coded in VBA language and developed specifically for analyzing freelist data in Microsoft Excel. Using FLAME, the investigator analyzed freelist data from all 22 participants in order to identify any items that referred to the same concept and to replace all instances with a common term. Additionally, FLAME was used to identify how many participants freelisted each item and to calculate each item’s salience using Smith’s (1993) method. Using this method, salience is defined as the sum of the item’s percentile

ranks divided by the total number of lists, or average percentile rank across lists (Smith, 1993).

Rank order data was recorded and analyzed using SPSS version 21. The study team used the informal method of cultural consensus analysis (CCA) (Weller, 2007). In doing so, the team used principal components method of extraction with no rotation to assess for the presence of a cultural consensus in the ranking of causal items for each cancer. In accordance with this method, the original data matrix was rotated to give a matrix in which participants were the columns and each ranked item was a row. This matrix was then transformed to a participant-by-participant correlation matrix using a reliability analysis. This produced a matrix of all 21 participants listed as both columns and rows and each cell containing the percent correlation between the complete rank order for the two participants. Principal component analysis was then carried out on this participant-by-participant correlation matrix. This procedure was done to analyze the breast cancer ranking data and repeated for the colon cancer ranking data. According to the methods of either formal or informal CCA a cultural model exists when the ratio of the first to second eigenvalue is 3:1 or greater. SPSS was also used for descriptive analysis of the participant population.

Calculation of sufficient sample size to conduct CCA is based on principles similar to calculating sample size in other types of quantitative analyses, namely the level of agreement between informants and the level of desired validity of results. Weller and Romney (1988) have published sample sizes for conducting this analysis based on the estimated competence level of the group of respondents (agreement between informants) and the desired proportion of agreement in aggregated responses. For this project, we

used stringent guidelines for conducting the analysis. Given that we did not yet know the general level of competence of informants on this topic, we assumed a relatively low level of estimated average cultural competence, specifically 0.50. In addition, we decided to strive for between 90% and 99% validity of the answers, ideally somewhere close to 95% validity. In this case, validity refers to the estimate of the correlation between the empirically obtained answers and the “true” culturally correct answers. Using these criteria and the published table, we arrived at a sample size of between 13 and 148 participants (Weller & Romney, 1988). Therefore, our sample of 21 participants who completed the ranking exercise met these guidelines, and using the Spearman-Brown prophesy formula this sample size would estimate a 94% accuracy at the 0.50 level of cultural competence.

Given that a sample of only 10 participants could be sufficient to identify the presence of a cultural consensus model, the informal model of CCA was also used on various subgroups of the sample according to demographic factors. These subgroups were chosen based on having at least 12 individuals and a theoretical basis for which the common demographic factor could influence a common cultural model. The resulting subgroups were of participants with: low acculturation level, highest education of some college or more, age under 40, and immigration to the US over age 18.

Stage I interviews were not fully transcribed but the investigator noted significant themes while abstracting freelist data from recordings of these interviews. Sections that significantly contributed to the understanding of emerging themes were later transcribed by the investigator. Stage II interviews were sent to a third-party company for full Spanish-to-Spanish transcription with the exception of one interview with a woman who



had only a first-grade education. This participant provided much less verbal data and the investigator was able to listen to this interview and transcribe relevant comments following initial thematic analysis of the other transcribed interviews.

Spanish language transcriptions were uploaded into the qualitative analysis software, Nvivo for Mac version 11.3.2. Using applied thematic analysis, the investigator developed an initial codebook based on both structural and content coding (Guest, Macqueen, & Namey, 2012). In developing the codebook, the investigator started with codes for themes that arose throughout interviews as recalled by the interviewer and recorded on the interview summary sheets. Examples of such codes include: ‘stress versus negative emotions,’ ‘personal experience with cancer,’ and ‘activation of genes.’ In addition, she added codes for each of the individual items that were ranked in relation to either breast or colon cancer and for each standard question on the interview guide including those in the section on models of disease inheritance. This allowed the investigator to organize data from the transcripts by topic and then identify emerging themes from further analysis within each topic. The codebook was revised iteratively and new codes were added, changed, and deleted according to the data. Some codes that were added included: ‘mammogram,’ ‘DNA,’ and ‘unique.’ These additional codes were identified during the coding process as the investigator read through transcripts and identified key words or concepts that arose across various interviews. Any new codes were retroactively applied to previously coded transcripts. The final codebook was applied to all 20 transcribed Stage II interviews, as well as to the sections transcribed by KF of Stage I interviews and the one Stage II interview not sent out for transcription.

## **Chapter 3 - Results**

### **POPULATION**

In total, 22 Latina immigrants participated in an interview. Ten women completed a Stage I interview and nine of these women went on to complete a Stage II interview as well. A total of 21 women completed a Stage II interview. The sample was fairly diverse in regard to age, time lived in the United States, country of birth, and education level. Participants' countries of origin spanned all regions of Latin America including Mexico, Central and South America, and the Caribbean. Nearly two-thirds of the sample was classified as being of a low level of acculturation according to the shortened version of SASH. See Table 1 for a complete summary of participant demographic characteristics.

**Table 1. Demographic Characteristics of the Study Population**

<b>Characteristic</b>	<b>Range</b>	<b>Mean (SD)</b>
Age (years)	21 - 57	38.7 (9.19)
Age moved to the US (years)	3 - 46	23.4 (12.7)
Time lived in the US (years)	2.5 - 27	14.8 (7.76)
<i>Country of Birth</i>	<b>Frequency</b>	<b>Percentage</b>
Argentina	1	4.55%
Bolivia	1	4.55%
Colombia	4	18.18%
Dominican Republic	1	4.55%
Ecuador	1	4.55%
El Salvador	6	27.27%
Guatemala	1	4.55%
Honduras	2	9.09%
Mexico	1	4.55%
Nicaragua	1	4.55%
Peru	3	13.64%
<i>Highest Education Level</i>		
Less than high school	2	9.09%
High school diploma	6	27.27%
Some college	3	13.64%
Bachelor's degree	5	22.73%
Graduate studies	6	27.27%
<i>Acculturation Level</i>		
Low	14	63.64%
High	8	36.36%

Participants also had a range of family cancer histories. None of the participants had any personal history of cancer, but most had at least one blood relative who had been affected by cancer. While not asked directly, one participant spontaneously shared that she had undergone genetic testing and was found to carry an inherited predisposition to breast cancer. This topic was discussed, but no further medical or genetic details were collected. See Table 2 for a summary of participants' family cancer histories. Of significance for this study, nine participants mentioned at least one relative who had been

diagnosed with breast cancer, while only three participants mentioned relatives diagnosed with colon cancer. After breast cancer, prostate cancer was the most commonly cited, with five participants mentioning at least one relative affected by prostate cancer. The other cancers that participants mentioned had affected their family members were: bone, brain, cervical, liver, lung, ovarian, skin, stomach, throat, thyroid, and uterine cancers as well as leukemia.

**Table 2. Summary of participants' family histories of cancer**

	<b>Number of participants</b>	<b>Percentage of participants</b>
<b>Individual affected with cancer</b>	0	0.00%
<b>FDR<sup>1</sup> affected with cancer</b>	10	45.45%
<b>SDR<sup>2</sup> or more distant relative affected with cancer</b>	17	77.27%
<b>At least one relative affected with breast cancer</b>	9	40.91%
<b>At least one relative affected with colon cancer</b>	3	13.64%

<sup>1</sup>FDR = First-degree relative

<sup>2</sup>SDR = Second-degree relative

## **CAUSAL ATTRIBUTIONS OF BREAST AND COLON CANCER**

### ***Cultural Consensus***

The final overall rank order of causes and risk factors along with freelist information for each cancer can be seen in Tables 4 and 5. Statistical analysis of the ranked data revealed no cultural model of the order of contribution to the development of breast and colon cancer in this population. This conclusion was reached based on the ratio of the first to second eigenvalues which was not 3:1 or greater. Consequently,

overall rank orders must be interpreted in light of the fact that no single cultural model is present and many risk factors were ranked close together. Given the relatively small sample size needed for this type of analysis, analysis of subgroups based on demographic factors was also possible. However, no cultural consensus model was identified for either cancer in any of these subgroups. Again, none of the ratios of first to second eigenvalues met the threshold of at least 3:1. See Table 3 for a list of the first and second eigenvalues and the corresponding ratios for the complete dataset and the various subgroups.

**Table 3. 1st and 2nd eigenvalues and ratio for full data set and subgroups**

<b>Dataset</b>	<b>Breast Cancer</b>			<b>Colon Cancer</b>		
	<b>1st Eigenvalue</b>	<b>2nd Eigenvalue</b>	<b>Ratio</b>	<b>1st Eigenvalue</b>	<b>2nd Eigenvalue</b>	<b>Ratio</b>
<b>All participants</b>	7.39	4.60	<i><b>1.61</b></i>	7.83	4.56	<i><b>1.72</b></i>
<b>Highest education of some college or more</b>	4.88	2.75	<i><b>1.77</b></i>	4.15	3.48	<i><b>1.19</b></i>
<b>Low acculturation</b>	5.26	2.77	<i><b>1.90</b></i>	4.47	4.10	<i><b>1.09</b></i>
<b>Moved to US over age 18</b>	4.36	4.19	<i><b>1.04</b></i>	5.08	3.80	<i><b>1.34</b></i>
<b>Under age 40</b>	6.12	2.39	<i><b>2.56</b></i>	5.73	2.29	<i><b>2.50</b></i>
<b>Born in Mexico, Central America, Caribbean</b>	5.22	2.41	<i><b>2.17</b></i>	5.92	2.35	<i><b>2.51</b></i>

**Table 4. Breast cancer causes and risk factors as freelisted and ranked by participants**

Cause or Risk Factor	Ranking		Freelisted by participants <sup>3</sup>		Smith's Salience
	Relative <sup>1</sup>	Average <sup>2</sup>	No.	%	
<b>Genes/Genetic Factors</b>	1	4.48	9	40.9%	31.4
<b>Hereditary Factors (Relatives who have had breast cancer)</b>	2	5.14	8	36.4%	29.6
<b>Hormonal Imbalance</b>	3	10.0	2	9.09%	8.02
<b>Radiation</b>	4	10.4	0	0.0%	0.00
<b>Being a woman (female sex)*</b>	5	10.5	2	9.09%	7.20
<b>Hormones/chemicals in food</b>	6	12.1	6	27.3%	12.4
<b>Eating processed food</b>	7	12.9	6	27.3%	12.8
<b>Smoking cigarettes or tobacco</b>	8	13.2	3	13.6%	5.63
<b>Preservatives</b>	9	14.4	1	4.55%	1.21
<b>Age (older age)</b>	10	14.6	1	4.55%	4.28
<b>Oral contraceptives*</b>	11	14.7	1	4.55%	3.03
<b>High-fat diet*</b>	12	14.8	1	4.55%	3.03
<b>Drinking a lot of alcohol*</b>	13	15.0	0	0.0%	0.00
<b>Medications</b>	14	15.2	2	9.09%	4.42
<b>Pollution in the environment</b>	15	15.7	4	18.2%	11.1
<b>Chemicals in skin products like deodorants and lotions</b>	16	15.7	3	13.6%	8.71
<b>Stress</b>	17	15.8	4	18.2%	8.28
<b>Lack of exercise</b>	18	16.2	7	31.8%	16.2
<b>Being overweight*</b>	19	16.4	2	9.09%	4.44
<b>Negative or unresolved emotions*</b>	20	16.5	3	13.6%	11.2
<b>Eating refined sugar</b>	21	16.8	2	9.09%	5.93
<b>Food colorings</b>	22	17.0	2	9.09%	5.30
<b>Having a child but not breast-feeding</b>	23	17.3	5	22.7%	11.4
<b>A hard hit or blow to the breast*</b>	24	17.3	4	18.2%	12.6
<b>Drinking sugary beverages like soda</b>	25	17.8	2	9.09%	7.68
<b>Race</b>	26	18.2	1	4.55%	0.91
<b>Using illicit drugs</b>	27	18.3	1	4.55%	3.33
<b>Not having biological children*</b>	28	19.4	1	4.55%	4.01

\*These items were not mentioned by at least 3 participants in the Stage I interviews but were included at the discretion of the research team. <sup>1</sup>Relative ranking is the ranking of the item relative to all other items based on the average ranking across all participants' rankings of that item. <sup>2</sup>Average ranking is the mean ranking across all participants' rankings of that item. <sup>3</sup>Number and percentage of participants who freelisted each item is based on participants who mentioned that item without category prompts. This leads to some total numbers to be less than the 3-participant cut off for inclusion in ranking.

**Table 5. Colon cancer causes and risk factors as freelisted and ranked by participants**

Cause or Risk Factor	Ranking		Freelisted by participants <sup>3</sup>		Smith's Salience
	Relative <sup>1</sup>	Average <sup>2</sup>	No.	%	
<b>Genes/Genetic Factors</b>	1	6.2	6	27.3%	18.6
<b>Hereditary Factors (Relatives who have had colon cancer)</b>	2	7.1	5	22.7%	14.9
<b>Colitis*</b>	3	7.7	3	13.6%	6.06
<b>High-fat diet</b>	4	8.2	7	31.8%	18.8
<b>Weakened Immune system</b>	5	9.2	0	0.0%	0.00
<b>Eating processed food</b>	6	10.3	4	18.2%	13.7
<b>Eating red meat</b>	7	10.7	2	9.09%	5.09
<b>Hormones/chemicals in food</b>	8	10.7	3	13.6%	9.31
<b>Radiation*</b>	9	10.9	1	4.55%	2.60
<b>Exposure to chemicals</b>	10	12.1	1	4.55%	0.909
<b>Drinking a lot of alcohol</b>	11	12.5	2	9.09%	8.59
<b>Drinking sugary beverages like soda</b>	12	13.4	2	9.09%	6.44
<b>Smoking cigarettes or tobacco</b>	13	13.4	1	4.55%	3.90
<b>Stress</b>	14	13.9	3	13.6%	3.98
<b>Food colorings*</b>	15	14.3	1	4.55%	3.90
<b>Being overweight*</b>	16	14.4	0	0.0%	0.00
<b>Using illicit drugs</b>	17	14.6	1	4.55%	0.758
<b>Pollution in the environment</b>	18	14.7	5	22.7%	12.2
<b>Type 2 diabetes*</b>	19	14.8	0	0.0%	0.00
<b>Negative or unresolved emotions*</b>	20	15.1	3	13.6%	4.38
<b>Lack of exercise</b>	21	15.9	3	13.6%	6.57
<b>Being a man (male sex)</b>	22	18.0	1	4.55%	0.505
<b>Age (older age)*</b>	23	18.3	0	0.0%	0.00
<b>Race</b>	24	19.1	0	0.0%	0.00
<b>Lack of sleep</b>	25	19.3	0	0.0%	0.00

\*These items were not mentioned by at least 3 participants in the Stage I interviews but were included at the discretion of the research team. <sup>1</sup>Relative ranking is the ranking of the item relative to all other items based on the average ranking across all participants' rankings of that item. <sup>2</sup>Average ranking is the mean ranking across all participants' rankings of that item. <sup>3</sup>Number and percentage of participants who freelisted each item is based on participants who mentioned that item without category prompts. This leads to some total numbers to be less than the 3-participant cut off for inclusion in ranking.

### ***Freelisting and Ranking***

On average, participants freelisted 7.23 (SD=4.55, Range=1-16) causes or risk factors for breast cancer and 6.5 (SD=3.47, Range=1-16) for colon cancer. This difference in means was not statistically significant. See Appendix E for a complete list of causes or risk factors that were freelisted by participants. Certain items were included in ranking because they met the threshold of being mentioned by three individuals in the Stage I interviews, but these items were only mentioned or more frequently mentioned in Stage I interviews when using category prompts. This was the case for “race,” “age,” and “using illicit drugs” for both breast and colon cancer as well as “radiation” and “preservatives” for breast cancer and a “weakened immune system,” “being of the male sex,” “lack of sleep,” “exposure to chemicals” and “smoking cigarettes or tobacco” for colon cancer.

“Genes/genetic factors” and “heredity factors” were the specific causes that were ranked highest for both breast and colon cancer. Nevertheless, the quantitative data shows that the average rankings of these factors were slightly lower with respect to colon cancer and that more individuals freelisted genes or hereditary factors when considering causes of breast cancer. The order in which a participant freelisted in regard to each cancer had no impact on this finding. See Table 6 for complete rankings and p-values. In fact, “genes/genetic factors” and “hereditary factors” were the most frequently freelisted and the most salient risk factors mentioned by participants in regard to breast cancer. Meanwhile, “high-fat diet” was the most frequently freelisted and most salient risk factor that participants mentioned in relation to colon cancer. “Genes/genetic factors” and “hereditary factors” were the second and third most salient colon cancer risk factors,



respectively. “High-fat diet” was ranked 4<sup>th</sup> as a risk factor for colon cancer in comparison to 12<sup>th</sup> as a risk factor for breast cancer.

**Table 6. Difference in freelisting of genes or heredity by cancer type and order of freelisting**

Cancer listed first	n # (%)	Breast cancer - freelisted genes or heredity			Colon cancer - freelisted genes or heredity		
		Yes	No	p-value	Yes	No	p-value
Breast	10 (45%)	6 (60%)	4 (40%)	p=0.746	4 (40%)	6 (60%)	p=0.392
Colon	12 (55%)	8 (67%)	4 (33%)		7 (58%)	5 (42%)	
<b>Total</b>	<b>22</b> <b>(100%)</b>	<b>14</b> <b>(64%)</b>	<b>8</b> <b>(36%)</b>	<b>--</b>	<b>11</b> <b>(50%)</b>	<b>11</b> <b>(50%)</b>	<b>--</b>

“Never having biological children” was freelisted by one participant outside the use of category prompts and ranked last in the ranking of risk factors from greatest to least role in the development of breast cancer. Similarly, “lack of sleep” was not freelisted by any participants outside the use of category prompts and ranked last in the ranking of risk factors from greatest to least role in the development of colon cancer. After the ranking task, participants were asked about any items included in the ranking task that surprised them as well as whether they felt anything was missing. Some participants mentioned one or more items that they felt were missing from either the breast or colon cancer ranking task. However, for the most part, participants felt that the lists were complete and included all significant causes or risk factors for each cancer. For breast cancer, the only items that were identified as missing by more than one individual were “breast implants,” “coffee/caffeine,” and “lack of medical care/screening.” In each case, two individuals mentioned each of these items. Participants mentioned being most surprised to see “a hard hit or blow to the breast” and “not having biological children” as possible causes or risk factors for breast cancer. In regard to colon cancer, again two participants mentioned “a lack of medical care” as a cause or risk factor that was missing

and two participants mentioned “hemorrhoids.” These two factors were somewhat related since those who mentioned hemorrhoids spoke about how they could lead to colon cancer if left untreated. Many participants were surprised by the inclusion of “type II diabetes” in the ranking for colon cancer factors. Participants also mentioned being surprised by “colitis”, “being of the male sex,” “lack of sleep,” and “a weakened immune system.” When asked about items that participants endorsed as contributing to either breast or colon cancer in the ranking exercise which they individually had not mentioned in the freelisting, most participants reported that these were items they had previously heard of or thought about in connection to cancer but that simply did not come to mind during the freelisting.

### ***Qualitative Themes***

In addition to quantitative analysis of participants’ freelists and rank orders, applied thematic analysis revealed several qualitative themes related to participants’ causal attributions of breast and colon cancer. Many of these themes revolved around participants’ discussion of individual risk factors, but some were more overarching and ran throughout participants’ discourse. Not only the most highly ranked or most salient risk factors stood out, but often discussion of those items that were ranked lower provided insight into the women’s causal attributions. Of particular interest, were factors that some women endorsed but others were surprised to see in the ranking exercise as described above. Below, these themes are grouped by the cancer they relate to or discussed together if they relate to both cancers.

## BREAST CANCER CAUSAL ATTRIBUTIONS

### *A hard hit or blow to the breast*

To begin, participants had a variety of interesting comments on the item “a hard hit or blow to the breast.” Overall, this item was ranked 24<sup>th</sup> of 28 risk factors for breast cancer. From the qualitative data, participants who elaborated on this topic fell into one of three categories in regard to this risk factor: those who had not previously heard of this in relation to causing breast cancer (7 women), those who had heard this idea but did not personally endorse it (2 women), and those who did ascribe to a model in which a hit or blow to the breast could cause breast cancer (7 women). In general, those who did endorse this as a possible cause of breast cancer described a process by which such a blow could cause cancer if the injury were not treated by a physician. As one participant explained,

“I’ve heard that yes, people who have been hit hard in the breast and haven’t had it checked out and they’ve left it untreated and they developed like a mass and then later in the future they’ve developed cancer.” (P111, age 45, El Salvador)

“He escuchado sí, de personas que han tenido un golpe fuerte en el seno y que no se han atendido y lo han dejado así y se les ha ido quedando como una masa y entonces después en el futuro han desarrollado un cáncer.” (P111, age 45, El Salvador)

### *Breast-feeding*

Building on the above theme, women engaged with the topic of breast-feeding in regard to breast cancer risk through discussing it spontaneously or freelisting it and also by expanding on thoughts around the item “having a child but not breast-feeding” as prompted by the interviewer in the ranking exercise. In ranking this item in regard to its role in the development of breast cancer, “having a child but not breast-feeding” was just above “a hard hit or blow to the breast” and with an overall ranking of 23 out of 28

factors. Although five women freelisted this item, its overall Smith's salience was slightly lower than that of "a hard hit or blow to the breast." In general, women tended to support the idea that breast-feeding could reduce a woman's risk of developing breast cancer, sometimes citing information read on-line or obtained in new mother classes. However, these same women were often less sure that the opposite was true, that *not* breast-feeding could actually raise one's risk.

"Well, I don't know if not doing it [breast-feeding] increases the risk, but I know that I've heard that doing it [breast-feeding] lowers your risk. So, maybe not doing it doesn't do harm, but doing it helps. So I put it there in the middle. I think I've definitely heard that it helps lower the risk." (P201, age 32, El Salvador)

"Bueno, no sé, si no hacerlo [amamantar] incrementa el riesgo, pero sé que he escuchado que hacerlo [amamantar] te baja el riesgo. Entonces, de pronto, no hacerlo no perjudica, pero hacerlo ayuda. Entonces lo puse por ahí en la mitad. Me parece que definitivamente he escuchado que ayuda a bajar el riesgo." (P201, age 32, El Salvador)

Other women followed the logic that if breast-feeding lowers risk, then not breast-feeding must raise one's risk of breast cancer.

"Yes, I just had a baby, and I was investigating a lot about breast-feeding and that was one of the things they told us. The fact of breast-feeding our children, well our babies, is going to prevent us from getting cancer. That it is a direct thing too, directly related. So, not doing it could then keep us from being able to fight cancer." (P202, age 35, Honduras)

"Sí, ahorita yo acabo de tener un bebé y estuve investigando también muchas cosas sobre la lactancia materna y eso era una de las cosas que nos decían. El hecho de dar de mamar a nuestros hijos, bueno a nuestros bebés, nos va a prevenir que pueda venir el cáncer. Esa es una cosa directa también, relacionada directamente. Entonces, el no hacerlo puede entonces evitar que podamos combatir el cáncer." (P202, age 35, Honduras)

Finally, another group of women simply saw no connection between breast-feeding and cancer risk. Often, this belief was based on anecdotal counter-examples. As one such woman explained,

“There are women who breast-feed, they have two, three children and they get cancer. So I don’t see any relationship,” (P106, age 48, Nicaragua)

“Hay mujeres que amamantan, tienen dos, tres niños y desarrollan cáncer. Entonces, no veo una relación.” (P106, age 48, Nicaragua)

When explaining how not breast-feeding could increase a risk for breast cancer, participants tended to refer to either a process of hormonal changes or the milk building up and causing problems similar to “a hard hit or blow to the breast.” As one participant responded when asked if she had thought about why not breast-feeding would cause breast cancer,

“Why? I believe that it’s related to the hormonal part. That’s what I think.” (P205, age 57, Colombia)

“¿Por qué? Yo creo que tiene relación con la parte hormonal, pienso yo.” (P205, age 57, Colombia)

Another participant explained,

“Yes, also it’s like the same as a hard hit to the breast because they had children or maybe they weren’t careful or they didn’t breast-feed or they breast-fed but they didn’t breast-feed well, so then they developed cysts there because cysts develop, the milk crystalizes, I don’t know, and if you aren’t careful in the future that can cause some type of cancer too. That’s what I’ve heard.” (P111, age 45, El Salvador)

“Sí, también es cómo lo mismo de un golpe fuerte en el seno, porque tuvieron hijos o tal vez no tomaron las precauciones o no amamantaron, o amamantaron pero no amamantaron bien, entonces como que se quedan los quistes ahí, porque se forman como unos quistes, se cristaliza la leche no sé y si no se tiene cuidado, en un futuro puede causar algún tipo de cáncer también. Eso es lo que he escuchado.” (P111, age 45, El Salvador)

Possibly, this similar perceived causal mechanism is reflected in the fact that ‘having a child but not breast-feeding’ and ‘a hard hit or blow to the breast’ had such similar overall average rankings in regard to their role in causing breast cancer.

#### *Not having biological children*

As mentioned previously, women were commonly surprised to see “not having biological children” included in the ranking exercise in regard to risk factors for breast

cancer. Consequently, many women stated that they did not think that not having children would impact a woman's risk of developing breast cancer. This can be seen quantitatively in that this item had the lowest overall ranking in terms of causing breast cancer even though it did not have the lowest Smith's salience in the freelisting task. Participants' general rejection of this cause of breast cancer was also captured qualitatively. For instance, one participant stated,

"No, I don't think it has much to do with the fact of not having children, there are many women who never in their life have children, they die at a good old age and they never get any type of cancer. So I think that not having children doesn't necessarily mean that a woman is going to get cancer." (P202, age 35, Honduras)

"No, no creo que tenga mucho que ver el hecho de que no tenga hijos, hay muchas mujeres que nunca en su vida tienen hijos, mueren en buena vejez y nunca les dio ningún cáncer. Entonces pienso que el no tener hijos, no necesariamente va a decir una mujer va a tener cáncer." (P202, age 35, Honduras)

However, some women did feel that not having biological children could impact a woman's breast cancer risk.

"Because I think that the female body is made to reproduce and at some moment the body expects to use – what it's made for because basically it's just be born, grow, reproduce, and die. And I think that in women if that doesn't exist, and they use a lot of [contraceptive] pills and hormones, preventing the natural cycle of the woman, that can also produce [cancer], because the breasts and something in the reproduction part, too. So I think that has a strong effect on women." (P212, age 34, Ecuador)

"Porque pienso que el cuerpo de las mujeres está hecho para reproducirse y en algún tiempo el cuerpo espera usar -- para lo que es porque básicamente es solo nacer, crecer, reproducirse y morir. Y pienso que en las mujeres si no existe eso y en cuidado mucho con pastillas y hormonas, no dejando el ciclo natural de la mujer, también puede producir [cancer], porque los senos y algo de la parte de la reproducción también. Entonces pienso que eso afecta de una manera fuerte en las mujeres." (P212, age 34, Ecuador)

Finally, some women actually thought that the opposite was true, that women who do have children are at greater risk of developing breast cancer than those who do not.

“Well, it depends if the people are... what’s the word?...sterile? I think that is a process that God allowed, that if he didn’t give that person the privilege of having children, he’s not going to cause... Because I think that what makes it that – It’s a woman’s pregnancies that activate the hormones in the breasts, so that the breast does have an activity. I think that because before getting pregnant, the breast doesn’t have milk, it doesn’t do those things. So I think that with pregnancy, you activate it, it’s like it really activates your body for your mammary system. And it starts – and so if you don’t have biological children then I don’t think that is ever activated... Yes, I think that there is more risk for the woman who has children than the woman who doesn’t.” (P213, age 39, Honduras)

“Bueno, depende si las personas son ¿cómo se dice? ¿Estériles? Yo pienso que ese es un proceso que Dios dejó que si a la persona no le dio el privilegio de tener hijos no va [inaudible] Porque yo pienso que lo que hace que -- Son los embarazos de uno que hace que se activen las hormonas en los pechos, que tu pecho si tenga una actividad. Eso pienso yo porque antes de salir embarazada uno no tiene leche, no hace esas cosas. Entonces pienso que con el embarazo uno activa, es como que activa en verdad tu cuerpo para tu sistema mamario. Y empieza -- y entonces si no tiene hijos biológicos pienso que no se activó nunca eso... Sí, yo pienso que es más riesgo la que tiene hijos que la que no tiene.” (P213, age 39, Honduras)

As demonstrated in the quote above, the reasoning for how having or not having children could influence a woman’s breast cancer risk was often attributed to pregnancy and birth as being related to hormones which participants believed play a role in breast cancer.

#### COLON CANCER CAUSAL ATTRIBUTIONS

##### *Diet*

As mentioned above, “high-fat diet” was the most salient risk factor for colon cancer in this population. This was part of the broader context in which participants saw diet as having a greater role in the development of colon cancer than breast cancer, a sentiment that participants expressed in relation to food items such as a high-fat diet, red meat, refined sugar, and others. As one participant stated,

“It seems to me that, in the case of colon cancer, it has to do with what you eat.” (P106, age 48, Nicaragua)

“Me parece que, en el caso del colon, tiene que ver con lo que se come.” (P106, age 48, Nicaragua)

Participants saw the increased role of diet in colon cancer as due to the way in which food comes into direct contact with the colon and the colon's function in processing that food.

"Everything goes through the colon."  
(P105, age 33, Mexico)

"Todo va por el colon." (P105, age 33,  
Mexico)

### *Type 2 diabetes*

"Type 2 diabetes" was a colon cancer risk factor that participants commonly mentioned as surprising to be included in the colon cancer risk ranking exercise. Overall, this item was ranked 19<sup>th</sup> of 25 potential causes or risk factors in regard to their role in the development of colon cancer, placing it between "pollution in the environment" and "negative or unresolved emotions." No participants freelisted this risk factor either spontaneously or when given category prompts. Since many participants expressed surprise at its inclusion, it is unsurprising that only three participants stated that they had heard of a connection between diabetes and colon cancer or cancer in general.

Conversely, many participants stated that they had not heard of any such association and could not really see what the connection might be.

"No. I hadn't heard. I know that diabetes obviously has to do with the regulation of sugar. So type 1, type 2, I don't know what the difference is. So I would say that it's a condition, the blood, the sugar, I don't know if all that has to do with the colon. So I put it there, below colitis." (P102, age 30, Colombia)

"No. No había escuchado. Sé que la diabetes obviamente tiene que ver con la regulación del azúcar. Entonces tipo 1, tipo 2, no sé qué es la diferencia. Entonces, dijera es una condición, la sangre, el azúcar, no sé qué tiene que ver con el colon todo. Entonces lo puse ahí, bajo de colitis." (P102, age 30, Colombia)

Those that had not previously heard of or considered a relationship between type 2 diabetes and colon cancer but still thought there could be one, often spoke of the



common factors that could cause both diseases or the fact that a person with diabetes was generally in poorer health overall and, therefore, more susceptible to any other illness.

“Well, I think, because it falls under excess – diabetes – when people drink a lot of sugary drinks or eat a lot of carbohydrates, too much fat, then also you’re stressing your stomach and consequently the whole digestive system. I hadn’t thought about it before but when I saw it, I think that it could be, it’s high in --. Also, it depends on the type of diet one has had, so I think that if you don’t take care of your diabetes it’s also going to affect the rest of the digestive system.” (P212, age 34, Ecuador)

“Pues yo pienso, porque cae en el exceso -- la diabetes ca- -- cuando toman muchas bebidas azucaradas, o comen muchos carbohidratos, grasas en exceso, entonces también estas dándole estrés al estómago y por ende a todo el sistema digestivo. No lo había pensado antes, pero cuando la vi, pienso que puede ser, es alta en --. También depende de la alimentación que uno haya llevado, entonces, pienso que si no te cuidas de la diabetes va a afectar también el resto del sistema digestivo.” (P212, age 34, Ecuador)

Possibly, this phenomenon of individuals not previously engaging with the idea of type 2 diabetes as contributing to colon cancer and yet imagining a way in which it could, may explain the fact that multiple participants were surprised by the inclusion of type 2 diabetes among possible colon cancer risk factors and yet this item did not have the lowest ranking in terms of risk for colon cancer.

“No, it just seemed to me... that it makes sense if you’re suffering from diabetes, well honestly I don’t remember what the difference is between type 1 and type 2, but I know that it’s an illness, for us, we consider it to be serious, so I think that weakens your immune system and you’re more susceptible to contracting other illness. So that’s why I put it a little higher.” (P201, age 32, El Salvador)

“No, solo me pareció...que it make sense que si estás padeciendo de diabetes, bueno la verdad no recuerdo cuál es la diferencia del tipo 1 y del tipo 2, pero sé que es una enfermedad, para nosotros que la consideramos grave entonces pienso que eso debilita tu sistema inmunológico y está más susceptible a contraer otras enfermedades. Entonces por eso lo puse un poco arriba.” (P201, age 32, El Salvador)

#### *‘Being a man’ or the male sex*

Another possible risk factor that was included for ranking with colon cancer and about which participants provided interesting insight, was that of “being a man or the

male sex.” This item arose purely from freelisting in stage I interviews and was not considered by the researchers prior to the Stage I interviews. Although only one participant mentioned this item entirely spontaneously, it arose more frequently when given category prompts, especially that of “demographic factors.” As mentioned above, this was also one item that various women mentioned surprised them. Quantitatively, this potential risk factor had an overall ranking of 22 out of 25 possible causes of colon cancer and had a similar average ranking to that of “age (older age).” Qualitatively, some women expressed their surprise at male sex as a possible risk factor for colon cancer in saying that it was a factor they had not previously considered and did not see the connection. One participant stated,

“I don’t think it has anything to do with it, we all have a colon.” (P105, age 33, Mexico)

“No creo que tenga algo que ver, todos tenemos colon.” (P105, age 33, Mexico)

Other women who did endorse this risk factor often based this risk on what they perceived as typical male behaviors that could lead to colon cancer. For example, one participant explained,

“Because I think that colon cancer is caused by a poor diet, by pollution in the environment, tobacco and alcohol have a great influence and men generally drink and smoke more than women.” (P104, age 47, Argentina)

“Porque yo creo que el cáncer de colon se da por una mala alimentación, se da por la contaminación del medio ambiente, el tabaco y el alcohol influyen demasiado y el hombre generalmente toma y bebe y fuma más que las mujeres.” (P104, age 47, Argentina)

Finally, at least one participant was unsure whether it was even possible for women to have colon cancer as demonstrated by her question:

“But do men and women get colon cancer or only men?” (P207, age 45, El Salvador)

“Pero, ¿el cáncer de colon les da a hombres y mujeres o solo a los hombres?”  
(P207, age 45, El Salvador)

## CAUSAL ATTRIBUTIONS RELEVANT TO BOTH BREAST AND COLON CANCER

While the causal attributions described above were more relevant to one cancer or another, many items were freelisted, ranked, and discussed in relation to both cancers, and much can be learned by highlighting the similarities and differences in the ways in which participants talked about these items in regard to each cancer.

### *Overlap in causal attributions of breast and colon cancer*

Participants often highlighted similarities between risk factors for breast and colon cancer, as reflected in the overlap of many of the most frequently freelisted items used in the ranking task. For many factors, participants saw these causes or risk factors playing similar roles in the development of both cancers or in cancer in general. As one participant stated,

“Radiation, exposure to chemicals, environmental pollution...It’s related to every type of cancer.” (P101, age 44, Dominican Republic)

“Radiación, exposición a químicos, la contaminación del medio ambiente...Está relacionado a todo tipo de cáncer.” (P101, age 44, Dominican Republic)

### *The role of genetics and heredity in cancer*

As reflected in the final rank orders of the risk factors for both cancers, participants generally expressed that “genes/genetic factors” and “heredity factors” play an important role in the development of both cancers. This was demonstrated qualitatively as well.

“It seems to me that those are the most important factors for a person to develop any type of cancer, the genetic and hereditary factors are very important.” (P111, age 45, El Salvador)

“Me parece que esos son los factores más importantes para desarrollar cualquier tipo de cáncer en una persona, los factores genéticos y hereditarios, son muy importantes.” (P111, age 45, El Salvador)

As the quote above shows, participants commonly talked about genetics and heredity in similar ways and often even used these terms interchangeably. It is important to clarify the difference between these two factors although many participants spoke about them similarly, as discussed below. All cancer is genetic, meaning that it is caused by genetic changes which allow the cell to replicate and proliferate unchecked. Most often these genetic changes occur within an individual sometime after birth. However, a minority of cancer cases are hereditary, meaning that a cancer predisposition runs in the family due to a heritable germline genetic variant. In addition to participants freelistings both items, part of the rationale for including both items for ranking was to tease out whether or not participants would endorse this difference. Most participants did not distinguish between the two concepts. This is seen in the following quote in which the participant specifically mentions genes but also talks about concepts related to heredity more generally such as affected family members and traits passing through generations.

“I think that they’re related because you inherit genetics from your parents so there you’re going to inherit, if they have a disease that they can transmit you’re going to inherit it so that is inheritance that you inherit with your genealogy. So for me, they go almost together.” (P201, age 32, El Salvador)

“Creo que vienen relacionados porque la genética la heredas de tus padres así que ahí lo vas a ir heredando si ellos tienen alguna enfermedad que ellos te lo pueden transmitir así que eso es lo hereditario que te heredan con tu genealogía. Así que para mí van casi juntos.” (P201, age 32, El Salvador).

Although participants tended to speak about “genes/genetic factors” and “hereditary factors” in similar terms, when asked directly whether or not they saw any difference between the concepts, three general types of responses were given. First, there were those who saw “genes/genetic factors” and “hereditary factors” as having the same meaning.

“For me, it’s the same. Because if your relatives have had cancer, you have it in the genes, because it’s hereditary.” (P111, age 45, El Salvador)

“Para mí, viene siendo lo mismo. Porque si tus familiares han tenido cáncer, lo tienes en los genes, porque es hereditario.” (P111, age 45, El Salvador)

Next, there were those who saw these concepts as very closely related and possibly having only a semantic difference.

“Genes are what you have, and inheritance is what someone has given you. What else can I say?” (P206, age 50, Colombia)

“Los genes es lo que uno tiene, y la herencia es lo que alguien le ha dado a uno. ¿Qué otra cosa puedo decir?” (P206, age 50, Colombia)

Finally, there were those who distinguished between the two concepts, and in doing so, tended to view “genes/genetic factors” as being more direct or unique to the individual while “hereditary factors” could be more distant or more generalized to the family.

“We have our own...how do you say it?...our own individual genetics, but the difference for me is that when we are created we have our own genetics that are going to say which illnesses we might have, but it comes from our parents, from our family, they come in the genes that are passed on when we’re born.” (P201, age 32, El Salvador)

“Tenemos nuestra propia, ¿cómo se dice?, nuestra propia genética individual, pero la diferencia para mí es que cuando nos creamos tenemos nuestra genética que va a decir las enfermedades que podemos traer pero viene por parte de nuestros padres, por parte de nuestra familia que vienen en los genes que se pasan al nacer.” (P201, age 32, El Salvador)

Regardless of exactly how the individual viewed the relationship between “genes/genetic factors” and “hereditary factors”, all participants expressed that these two factors worked together or went hand-in-hand.

“Well, I don’t know, what I understand is that in your chain of DNA you inherit part of both parents, I imagine that that goes hand-in-hand with the hereditary factors.” (P101, age 44, Dominican Republic)

“Bueno no sé, lo que tengo entendido es que en tu cadena de DNA heredas parte de ambos padres, me imagino que eso con los factores hereditarios van de la mano.” (P101, age 44, Dominican Republic)

Even if participants saw these concepts as having the same meaning, they were forced to decide which plays a greater role in the development of each cancer in the ranking exercise. As shown in the rank order data presented in Tables 4 and 5, most participants indicated that “genes/genetic factors” play a larger role than “hereditary factors” in the development of both cancers. Possibly, this ranking was related to the previous quotes describing genetics as being more immediate or having a more direct role than hereditary factors in the health of the individuals. However, given that many participants saw these two risk factors as the same or closely related, they will be discussed collectively as ‘genetics and heredity’ from this point forward.

When talking about genetics and heredity in relation to breast and colon cancer, two interesting and related themes recurred throughout interviews. First, participants often spoke about genes as being somehow latent or dormant in one’s body and subsequently being “activated” or “triggered” by environmental or lifestyle factors to induce cancer.

“Yes because they’re congenital they aren’t unleashed unless you provoke them in the environment.” (P105, age 33, Mexico)

“Sí, porque están congénitos no se desatan a menos que uno en un ambiente lo provoque.” (P105, age 33, Mexico)

Secondly, participants often spoke of individuals who had genetic or hereditary risk factors for cancer as being “prone” to cancer, but they did not see this risk as 100%

“I think that [genetic factors] play a role but I think that if you can maintain a good diet, a good lifestyle, I think that those genes can be there and they aren’t going to, they aren’t going to develop.” (P108, age 39, El Salvador)

“Yo creo que [los factores genéticos] juega un papel pero creo que si uno puede mantener una buena alimentación un buen estilo de vida creo que los genes pueden estar ahí y no van a... no van a desarrollarse.” (P108, age 39, El Salvador)

As described above, participants commonly reported a similar role of genetics and heredity in the development of both cancers, but those who distinguished between the role in each cancer tended to recognize a greater role of genetics and heredity in the development of breast cancer than in colon cancer.

“I see it because I see the experiences that I’m familiar with. Like with breast cancer...immediately you think ‘ah, someone else has it too.’ But colon cancer, no, it’s like you relate it more with... I relate colon cancer more with dietary habits and lifestyle in terms of emotional aspects.” (P106, age 48, Nicaragua)

“Lo veo por lo que veo de las experiencias que conozco. Como que el cáncer de seno esta lo...inmediatamente piensa “ah, alguien lo padece también”. Pero de cáncer de colon no, es como lo relacionas más con... yo lo relaciono al cáncer de colon con hábitos alimenticios y estilo de vida en cuanto a emocional.” (P106, age 48, Nicaragua)

However, the greater attribution of breast cancer to genetics may have been due to the greater general awareness of breast cancer found in the sample. This point is discussed in more depth below. One participant explained that she had specifically heard of the role of genetics in breast cancer but not in colon cancer.

P101, age 44, Dominican Republic: “I’m not sure, because I don’t know much about colon cancer, I haven’t heard much about colon cancer. I imagine that it is probably similar to other cancers.”

Interviewer: “So you’ve heard more about genetics specifically for breast cancer?”

P101: “Yes, breast cancer, yes.”

P101, age 44, Dominican Republic: “No estoy segura, porque no sé mucho sobre cáncer en el colon, no he escuchado mucho sobre cáncer de colon. Me imagino que debe ser similar a los otros cánceres.”

Entrevistadora: “¿Entonces en cuanto a la genética eso has escuchado específicamente para cáncer de seno?”

P101: “Sí, cáncer de seno sí.”

### *The role of the psyche in cancer and disease*

Few participants denied the power of psychological factors, including stress and negative emotions, to influence health and within this to cause cancer. Those who did reject this cause, did not see the connection between the physical and the mental or did

not see evidence for this connection. For instance, when asked about stress playing a role in cancer, one participant responded

“Because, I don’t think that – since we all have problems, we would all get cancer, women would. So, I see that we all have problems, so – they are things that can be resolved and we aren’t going to get cancer because of them.” (P207, age 45, El Salvador)

“Porque, yo no creo que -- si todo mundo tenemos problemas, a todos nos diera cáncer, a las mujeres sí. Entonces, yo veo que todos tenemos problemas, entonces -- son cosas que se pueden solucionar y no por eso nos va a dar cáncer.” (P207, age 45, El Salvador)

Conversely, many of the women saw a clear connection between one’s mental state and health in general, not just cancer. These women commonly mentioned the way that psychological distress can weaken the immune system.

“I think that stress can contribute to all illnesses. Because if you’re stressed, it can make a --it can weaken their immune system and they can become the victim of anything, of cancer, of -- whatever, any illness.” (P205, age 57, Colombia)

“Yo pienso que el estrés pues contribuye para todas las enfermedades. Porque si una persona tiene estrés puede hacer una --se le pueden bajar sus defensas y ser víctima de cualquier cosa de cáncer, de -lo que sea, cualquier enfermedad.” (P205, age 57, Colombia)

Furthermore, part of this model was that stress is rarely the sole cause of cancer but rather works together with other risk factors to set off an underlying disease or predisposition or leads to poor health habits which ultimately brings about illness.



“Well I think that stress is a bomb in your body, because, this, it can develop, not just colon cancer, it can develop even a stroke. So, I really do think stress is a bomb in your body, in your organism. And so it can develop colon cancer, breast cancer. Because, well scientifically, they say that some of the genes are there, they just aren’t active. So I think that stress is one of the things that activates them, that – activates any illness in your body.” (P213, age 39, Honduras)

“Pues yo pienso que el estrés es una bomba en tu cuerpo, porque, este, te puede desarrollar, no solo cáncer de colon, te puede desarrollar hasta un ataque al cerebro. Entonces, yo realmente si pienso que el estrés es una bomba en tu cuerpo, en tu organismo. Y tanto puede desarrollar cáncer de colon, cáncer de mama. Porque, bueno científicamente dicen que los genes unos están ahí, nada más que no están activos. Entonces yo pienso que el estrés es una de las cosas que los activa, cual -- activa cualquier enfermedad en tu cuerpo.” (P213, age 39, Honduras)

Throughout these discussions, participants raised the idea that stress and negative emotions have to be dealt with and released from the body, and if an individual does not do this, the body would do so through illness.

“Look, I think that our body is like, I always symbolize it like when a pressure cooker, when you’re cooking, a pressure cooker, that pressure cooker the more that it contains, at some point it’s going to explode, right? I think that human beings in general and women, if we’re talking about women, there are a lot of things that women are repressing, like containing...It’s like you’re loading yourself, you’re loading yourself and your body gets to a point in which it’s going to burst.” (P105, age 33, Mexico)

“Mira yo pienso que nuestro cuerpo es como, yo siempre lo simbolizo como cuando la olla de presión, cuando cocina uno, una olla de presión, esa olla de presión mientras más se contiene, en algún momento va a explotar, no? Y creo que en los seres humanos en general y en las mujeres si hablamos de más mujeres, hay muchas cosas que las mujeres están guardando, como conteniendo...Es como que te estás cargando, te estás cargando y tu cuerpo llega a un momento en que va a dispararlo por algún lado.” (P105, age 33, Mexico)

Other participants employed a more biochemical model and described stress as causing a buildup of harmful chemicals that causes disease.

“...I understand that according to the studies when you’re stressed, your body accumulates certain chemicals and if your body isn’t processing them and you’re constantly accumulating these chemicals because you’re constantly anxious, nervous, stressed, I think that will also be detrimental for your health in general.” (P101, age 44, Dominican Republic)

“...entiendo que según los estudios cuando estas estresado tu cuerpo se agrega ciertos químicos y si tu cuerpo no los está procesando y tu estás constantemente agregando estos químicos porque constantemente estas ansiosa, nerviosa, estresada, yo creo que eso también va a ser detrimento para tu salud en general.” (P101, age 4, Dominican Republic)

Several participants also mentioned the positive power of the mind to cure or prevent illness, including cancer.

“Ah, increase the risk, yes, I think that the psychological aspect is very important because there are people that have gotten better when they tell them, no, you don’t have a chance, and they don’t believe it. I think that yes, the power of psychology is very strong, more than everyone thinks. So I think that the psychological can raise, could raise, or improve, to get better.” (P102, age 30, Colombia)

“Ah, aumentar el riesgo, sí, yo creo que lo psicológico es muy importante porque hay gente que ha superado cuando le dicen, no, no tienes chance y ellos no creen, yo creo que si el poder psicológico es bien fuerte más de lo que piensa todo el mundo. Entonces yo creo que lo psicológico puede aumentar, pudiera aumentar o mejorar, para mejorarse.” (P102, age 30, Colombia)

Most participants saw stress and negative emotions as going hand-in-hand and having a similar impact on health. However, those who distinguished between the two tended to see stress as playing a greater role in the development of cancer but often struggled to articulate why.

Similarly, many participants viewed stress and negative emotions as having the same impact on the development of both breast and colon cancer. However, some felt that stress plays a greater role in one or the other. For those who made this distinction, this tended to be based either on mental distress having a hormonal impact and being a greater risk factor for breast cancer or mental distress directly causing problems in the gastro-intestinal tract and being a greater risk factor for colon cancer.

“Well I think that breast cancer also has a lot to do with one’s hormonal changes... And stress is hormonal more than anything else,” (P213, age 39, Honduras)

“Bueno pienso que el cáncer de seno también tiene que ver mucho con el cambio hormonal de uno...entonces el estrés es más que todo hormonal.” (P213, age 39, Honduras)

“Because stress and all that creates emotions more in the stomach than in the breast, it causes more stomach aches. So it’s more related [with colon cancer] than with breast cancer.” (P206, age 50, Colombia)

“Porque el estrés y todo eso da más emociones en el estómago que en el seno, causa más molestias estomacales. Después está más relacionado [con el cancer de colon] que con el cáncer de seno.” (P206, age 50, Colombia)

### *Race*

Finally, the women shared interesting thoughts on the importance of race in causing both breast and colon cancer. Participants were fairly evenly divided on their endorsement of race as a risk factor for breast cancer. Some women specifically did not see a race-based increase in risk.

“Because, like I said at the beginning, I think that anyone can get cancer, and not just in the breast. I don’t think that race matters much. And I’ll give you examples, my family, we’re Latino, the woman that died that I told you about, she’s American, she’s white, and the other woman that works, that they removed her breast, she’s Filipino. So those are different races that don’t have anything to do with if they’re white or if they’re dark skinned.” (P209, age 55, Peru)

“Porque, como te dije al principio, yo creo que a cualquiera le puede dar cáncer, y no solo al seno. No creo que la raza tenga mucha importancia. Y te doy los ejemplos, mi familia nosotros somos latinos, la señora que falleció que te conté, es americana, es blanca y la otra señora que trabajaba, que le sacaron el seno es filipina. Entonces, son diversas razas que no tienen nada que ver con si son blancas o son morenos.” (P209, age 55, Peru)

A strong theme among those who did feel that race plays a part was the perception that Latina or Hispanic women are at a higher risk of breast cancer than those of other races. Most women who identified a specific race or ethnicity as being at increased risk, stated that Latinas had higher risk than others. After Latinas, women often mentioned women of African descent as being at increased risk of breast cancer over

non-Hispanic white women. As one participant described,

“I’ve always heard that Latina women have more or African women have a greater chance of having breast cancer than an American or white woman.” (P109, age 27, Bolivia)

“Siempre he escuchado que las mujeres latinas tienen más o las mujeres africanas tienen la posibilidad de tener cáncer de seno más grande que una persona americana o blanca.” (P109, age 27, Bolivia)

Those who believed race does influence cancer risk tended to attribute this to genetic differences between the races and/or as a product of cultural differences in regard to diet and behaviors.

“Race, well it could be like hereditary, when you say race.” (P209, age 55, Peru)

“La raza, bueno puede ser esto como hereditario, cuando dice la raza.” (P209, age 55, Peru)

“Like we’re the minority or that...I don’t know, because it’s like a combination of diet, the type of diet we have, is a diet, the lifestyle that we have is a different lifestyle than the Anglo-Saxons, so it’s like we’re more prone to develop this type of cancer.” (P111, age 45, El Salvador)

“Como que somos la minoría, o que... no sé, porque es como una combinación de la alimentación, del tipo de alimentación que nosotros tenemos, es una alimentación, el estilo de vida que nosotros tenemos es un estilo de vida diferente que los anglosajones, entonces, como que estamos más propensos a desarrollar este tipo de cáncer.” (P111, age 45, El Salvador)

Generally, these themes were the same when the women talked about race in regard to either breast or colon cancer risk. However, some women saw race as contributing less to colon cancer than to breast cancer or in some cases, not at all. This can be seen in the following exchange with the same participant who strongly endorsed the idea that Latina and African American women are at greater risk of breast cancer than other races.

Interviewer: “And race? I think that in breast cancer you had it higher up.”

P109, age 27, Bolivia: “Yes, because I’ve heard that a Latina woman or an African woman has more elevated risks than an American woman, or something like that.”

Interviewer: “But it’s not the same for colon cancer.”

P109: “No, I think that it can be any person.”

Entrevistadora: “¿Y la raza? Creo que para el cáncer de seno lo tenías más arriba.”

P109, age 27, Bolivia: “Sí, porque he escuchado que la mujer latina o una mujer africana va a tener riesgos más subidos que una mujer americana, o algo así.”

Entrevistadora: “Pero en cáncer de colon no es así.”

P109: “No, pienso que cualquier persona.”

## OVERARCHING QUALITATIVE THEMES

In addition to risk factors which participants discussed in freelist and ranking, there were several themes which emerged across interviews in participants’ discussions of their causal attributions for these two cancers.

### *The role of personal experience in ranking*

In both freelist and ranking of causes and risk factors, participants would often refer to their own experiences with family and friends who had developed cancer. For some participants, these experiences seemed to play a large role in their models of risk for these diseases, and they struggled to endorse any item that did not fit with their lived experiences. For instance, one participant stated,

“Being overweight. No, because the women that I saw that had cancer, they weren’t – they had a normal weight.”  
(P207, age 45, El Salvador)

“Estar con sobrepeso. No, porque las señoras que yo vi que tuvieron cáncer, no estaban -- tenían peso normal.”  
(P207, age 45, El Salvador)

### *Varying familiarity with the two types of cancer*

Participants were generally more familiar with breast cancer than colon cancer. This was seen in the slightly greater average number of items freelisted for breast cancer

than for colon cancer. This phenomenon was also captured qualitatively, with multiple participants mentioning that they had heard less about colon cancer than about breast cancer or other types of cancer. When asked if she had heard of colon cancer, one participant responded,

“I’ve heard of it but not as much as other cancers. For women, it’s more common that they get checked for breast and cervical cancer, not so much colon. No, it’s like it’s in the back of your mind, you don’t think about it as frequently.” (P201, age 32, El Salvador).

“He escuchado, pero no tanto como de otros cánceres. Para las mujeres es más común que se chequeen por el cáncer de pecho y de cervix, no tanto del colon. No, es como están atrás de la mente, no se piensa tan seguido.” (P201, age 32, El Salvador)

In answering the same question, another participant showed how some participants were not sure where the colon was located in the body.

P214, age 33, Guatemala: “Yes, I’ve heard of it but – I don’t really know much about that—“

Interviewer: “Do you know what the colon is?”

P214: “The colon? Yes, I think that it’s the part where – the colon – colon – Yes, it’s like a part here in the stomach, right?”

P214, age 33, Guatemala: “Si he escuchado, pero -- hasta, no se mucho sobre eso --“

Entrevistadora: “¿Sabe que es el colon?”

P214: “¿El colon? Sí, pienso yo que la parte donde -- el colon -- colon -- Si, es como una parte aquí en el estómago, ¿no?”

A couple women suggested they may have heard less about colon cancer because it might be seen as more of a taboo topic than other types of cancer.

“No one and I don’t know if it’s because it’s the type of cancer that people probably don’t want to talk about. I don’t know, but no, I don’t know anyone [with colon cancer], which is interesting.” (P101, age 44, Dominican Republic)

“Nadie y no sé si es porque es el tipo de cáncer que la gente probablemente pues no quiere hablar. No sé, pero no, no conozco a nadie [con cancer de colon], que es interesante.” (P101, age 44, Dominican Republic)

Finally, this was also seen in the fact that throughout interviews, three participants spontaneously mentioned colonoscopy as a screening for colon cancer, while eight women talked about mammography when discussing breast cancer.

### *Additive nature of risk factors*

One common theme raised by participants in discussing causes and risk factors for each cancer was the way in which various risk factors may work together or add together to cause cancer. For example, in discussing the risk for colon cancer, one participant remarked,

“Because the colon is like a processing gut where everything is processed and to me it seems like a man, if he does hard physical labor and has a poor diet and at the same time has diabetes and if he has intestinal problems and drinks and smokes then, yes it’s likely that he’ll develop [cancer]. He has a lot of risk factors for developing colon cancer.” (P104, age 47, Argentina)

“Porque el colon es como una tripa de procesamiento en donde se procesa todo y me parece que el hombre, si trabaja físicamente fuerte y tiene una mala alimentación y a la vez tiene diabetes, si tiene cólicos y toma y fuma, entonces, sí, es probable que desarrolle [cancer]. Tiene muchos factores, ya con esto, tiene muchos factores ya para desarrollar el cáncer del colon.” (P104, age 47, Argentina)

This was also a common theme in discussing the way in which environmental or lifestyle factors could combine with a genetic predisposition to cancer.

“...maybe if you’re stressed and you don’t have hereditary factors, nothing will happen. But if you have hereditary factors and you’re stressed all the time, I think the risk is higher that you could contract illnesses.” (P212, age 34, Ecuador)

“...tal vez si tu estás estresado y no tienes factores hereditarios, no va a pasar nada. Pero si tienes factores hereditarios y vives estresado toda la vida, creo que es más alto el riesgo de que puedas contraer las enfermedades.” (P212, age 34, Ecuador)

### *Natural versus Unnatural*

Another overarching theme throughout interviews in discussing the causes of cancer was that of doing or consuming things that were not seen as natural for the body.

“I think that cancer comes... Yes, it’s a... it’s basically, maybe, because it’s manipulating a natural process, like the cells and the organisms with -- that producing food with cows that they don’t give drugs and all that, they’re disrupting the natural. So I think that food that’s not natural, when a person eats that, I think cancer comes from there, from everything that’s happening. All those modern processes.” (P102, age 30, Colombia)

“yo creo que el cáncer viene... Sí, es una...es básicamente, de pronto, porque se está manipulando el proceso natural, como las células y los organismos con -- eso producir la comida así con vacas así que no les dan drogas y eso, están alterando lo natural. Entonces, creo que esa comida no es natural, entonces cuando uno se come eso, yo creo que, de ahí, de todo lo que está pasando viene el cáncer. Todos esos procesos modernos.” (P102, age 30, Colombia)

While consuming “unnatural” items such as processed food, too much hormonal birth control, and “synthetic” sweeteners was a common way for women to raise this theme, many also spoke of unnatural actions such as breast augmentation surgery, not having children, not breast-feeding, and using deodorant with chemicals as not being moral or upsetting the “normal cycle” and possibly increasing the risk of cancer. This way of thinking even influenced the way in which women incorporated new ideas into their models of cancer risk as exemplified by one participant’s comment when asked if any of the causes/risk factors provided for ranking in regard to breast cancer surprised her.

“Not having children, never before, but now that I think about it a bit more, I mean, the body is made, well the female body, we have to reproduce, otherwise, well, in my head I’m thinking, so I don’t know if it’s true. If we don’t let our body do what it has to do like any other animal, there are consequences. But I’m not sure, and I had never heard it before, I’m just now thinking about it.” (P109, age 27, Bolivia)

“No tener hijos por la única vez, pero ahora que lo pienso un poco más, o sea, el cuerpo está hecho, bueno el de la mujer, es que tenemos que reproducir sino, bueno estoy pensando en mi cabeza así que no sé si es verdad. Si no dejamos al cuerpo hacer lo que tiene que hacer como cualquier animal, por ahí tiene una consecuencia. Pero no sé y nunca lo había escuchado, solo que ahora lo estoy pensando.” (P109, age 27, Bolivia)



### *Modifying risk*

Both the themes discussed above, risk factors adding together and unnatural things causing cancer, blended into another theme that was common across interviews, which was the ways in which an individual can take actions to modify or reduce her risk of developing cancer. For example, one participant stated,

“I think that colon cancer like breast cancer can be avoided. I think that they can be avoided, I mean everything is according to living a healthy lifestyle with exercise and eating right.” (P108, age 39, El Salvador)

“Creo que el cáncer de colon como el de mama se pueden evitar. Yo creo que se pueden evitar, o sea todo es de acuerdo a un estilo de vida que uno lleva saludable, en ejercicio, comer bien.” (P108, age 39, El Salvador)

This concept of modifying risk was especially salient in regard to modifying a genetic or familial predisposition, as illustrated in the excerpt below.

“I think that you always need several [factors]. You can have hereditary factors, but if you have a good lifestyle, a good diet, you don’t eat too much fat, you don’t get stressed, or you don’t take drugs, I think you can avoid it. But if, even though you know you’re hereditary and you don’t take it seriously, then it’s more than sure that you’re going to acquire it.” (P212, age 34, Ecuador)

“Yo creo que necesitas varios [factores] siempre. Puedes tener factores hereditarios, pero si tú llevas un buen estilo de vida, una buena alimentación, no comes tanta grasa, no te estresas, o no tomas drogas, creo que puedes evitar. Pero si es que, a pesar de que sabes eres hereditario y no tomas ninguna importancia, pues es más seguro que lo vas a adquirir.” (P212, age 34, Ecuador)

Despite the sentiment that an inherited cancer risk could be modified, participants also acknowledged the degree of such a risk and that sometimes cancer could not be prevented entirely. These ideas were not mutually exclusive, and some participants discussed means of preventing cancer even in the face of a cancer running the family while also recognizing that it may not always be possible to prevent but only to delay the onset.

“If it’s genetic, it’s going to influence a lot the way that you develop the disease. And even when you protect yourself with things, I mean, even if you avoid these things, preventing that cancer is going to be very difficult, because it was already in your family or it was already a genetic factor.” (P107, age 36, Colombia)

“Si es genética sí va a influir mucho en la manera en que vas a desarrollar la enfermedad. Y aun cuando te proteges con cosas, o sea si evitas estas cosas igual prevenir ese cáncer va a ser muy difícil, porque ya estaba en tu familia, o ya era un factor genético.” (P107, age 36, Colombia)

Participants also discussed mammography as a screening measure for breast cancer and a way to lessen the impact of cancer. However, some participants were ambivalent about mammography, mentioning they feared that the radiation or pressure involved in a mammogram could actually put one at risk of developing breast cancer.

“When you go to do those mammogram exams, it’s horrible how they press [the breast], it’s excessive. I say, maybe this could cause it, maybe I don’t have anything but – it’s just they use so much force and I think that maybe that could have an effect.” (P207, age 45, El Salvador)

“Es que cuando uno se va a hacer esos exámenes de mamogramas, es una forma horrible como se lo presionan [el pecho], es exagerado. Yo digo, tal vez esto me lo puede provocar, tal vez no tengo nada, pero -- es que lo hacen con tanta fuerza y yo pienso que tal vez eso puede afectar.” (P207, age 45, El Salvador)

## **MENTAL MODELS OF DISEASE INHERITANCE**

Following the discussion of causal attributions of breast and colon cancer, participants were asked several questions related to disease inheritance in general, not specifically associated with cancer. The major themes were around genetics as associated with relatives, the characteristics that can be inherited, genetic predispositions, the genetic terminology used, and a pervading uncertainty about genetic knowledge.

### ***Genetics associated with relatives***

First, when asked what concepts participants associate with the word “genetics”, many participants mentioned thinking of relatives, especially their parents.

“In the genes, in everything that is transmitted from parent to children, in families that have – everything that’s in your branch of – of your family, all the - -. That whole part, all the diseases, the good things and bad things, intelligence, likes. I think that everything is transmitted, it’s like the memory that goes, from your family, in your body for all – It’s like the biological book of all families.” (P212, age 34, Ecuador)

“En los genes, en todo lo que se transmite padres a hijos, de familias tienen que -- todo lo que está adentro de tu rama de -- de tu familia, toda la ge --. Toda esa parte, todas las enfermedades, las cosas buenas y malas, la inteligencia, el gusto por algo. Pienso que todo se transmite, es como la memoria que va, de tu familia, en tu cuerpo para toda -- Es como el libro biológico de todas las familias.” (P212, age 34, Ecuador)

If asked how to describe genetics to another person, many participants used inheritance from one’s parents, and sometimes grandparents, to do this.

“Genetics is – it goes from... from the grandfather to the father, from the father to the son. And they are like the characteristics and qualities of a person that they have inside and that go on transmitting from generation to generation.” (P207, age 45, El Salvador)

“La genética es -- va de... del abuelo al papá, del papá al hijo. Y que son como las características y las cualidades de una persona que tienen en su interior y que va transmitiendo de generación en generación.” (P207, age 45, El Salvador)

Participants also recognized that although genes tie families together and are responsible for many of the traits shared among relatives, each individual has his or her own specific mixture of genes, which makes each person unique.

“I would say, well, it’s related with like I said earlier, it’s something that your genes are, you’re yourself, you’re you that was born with those, they’re what your dad and your mom gave you when they made you and that is what you are, you’re unique.” (P206, age 50, Colombia)

“Le diría, bueno es relacionado como le comenté antes, es algo, que son tus genes, eres tú misma, eres tú que naciste con esos son los que te dieron tu papá y tu mamá al crearte y eso se lo haces tú, eres única.” (P206, age 50, Colombia)

### ***What can be inherited***

In describing genetics, participants mentioned a variety of traits they consider to be heritable. These included physical traits such as hair and eye color, weight, build, and

blood type. It also included health traits such as predisposition to various illnesses.

Participants also mentioned more abstract qualities such as intelligence, talents, likes and dislikes, and personality traits.

“The character that you have also like how it is in genetics like that you bring that, how can I say it, if your dad is like very angry, then you also are prone to being a bit angrier, like more like your dad.” (P108, age 39, El Salvador)

“...el carácter que tiene uno también como que es como en la genética como que uno trae esa -- como le digo que, si su papá es como muy enojado, pues usted también tiene propenso a ser un poco como más enojado, como más al papá.” (P108, age 39, El Salvador)

When asked specifically about any genetic conditions or illnesses in their families or asked what conditions they think of when they think of genetic disease, participants most commonly referred to common complex diseases, such as diabetes, cancer, heart disease, hypertension and depression rather than more traditionally Mendelian genetic conditions.

“I think it’s a very strong factor, I think that cancer is, other illnesses, I don’t know, like diabetes, like heart problems, I think that many illnesses are linked to the hereditary factor.” (P101, age 44, Dominican Republic)

“Creo que es un factor súper fuerte, creo que el cáncer lo es, otras enfermedades, qué se yo, como la diabetes, como problemas del corazón, creo que muchas enfermedades están vinculadas con el factor hereditario.” (P101, age 44, Dominican Republic)

However, some participants did mention more directly genetic conditions. For example, several participants mentioned Down Syndrome as a genetic condition and a couple mentioned dwarfism. A few participants seemed to conflate infectious transmission from mother to child with genetic transmission of a disease.

“They can turn out dwarfs, that comes from genetics. It can transmit diseases, it can transmit some type of disease like AIDS, hepatitis can also be transmitted if the mother is sick with that type of illness, there are a lot of diseases that can be transmitted by genes.” (P209, age 55, Peru)

“Pueden salir enanos, eso viene de una genética. Puede transmitirlo enfermedades, puede transmitir algún tipo de enfermedad como el SIDA, hepatitis también puede transmitirle, si la madre está enferma de ese tipo de enfermedades, hay muchas enfermedades que le puede transmitir por medio de los genes.” (P209, age 55, Peru)

### ***Genetic predisposition: inborn and modifiable***

In discussing the ways in which genes influence health, many participants talked about the possibility of genes or illnesses developing or being triggered. This was similar to the way in which many participants talked about genetics and heredity in regard to breast and colon cancer but shows that they do not hold these beliefs only in relation to cancer but in relation to other illnesses as well.

“That’s what has an effect. That’s why I say that we can have genes that are there, like hidden, not hidden but that are asleep so any activity can, an external impact can trigger them.” (P105, age 33, Mexico)

“Eso es lo que influye. Por eso digo que podemos tener genes que están así como guardados, no guardados pero que están dormidos entonces cualquier actividad puede, un impacto externo los puede desatar.” (P105, age 33, Mexico)

In this same vein, participants also explained how individuals can take actions to modify or mitigate their genetic predispositions.

“...definitely genes have a – they’re an important marker, and according to that each person should know what they should do to prevent what they already bring in their genetic load. For example, I know that my dad died of colon cancer, I’m on top of my colonoscopy, I have a good diet in which I avoid fat and red meat.” (P205, age 57, Colombia)

“...definitivo los genes tienen una --son un marcador importante, y de acuerdo a eso cada persona debe saber qué debe hacer para prevenir lo que ya trae en su carga genética. Por ejemplo, yo sé que mi papá murió de cáncer de colon, yo estoy pendiente de mi colonoscopia, yo tengo una alimentación que evito las grasas y las carnes.” (P205, age 57, Colombia)

As shown above, these two themes appeared to be two sides to the same idea. According to participants, the general idea is that genes are lying underneath the surface and an individual takes actions such as eating well to protect herself from or mitigate the effects of genetics but may also do or encounter things that “set off” the genes and causes illness.

### *Use of genetic terminology*

The language that participants used to discuss and describe genetics was interesting in that there were some very loose associations between the words used and an individual’s education level. For example, it was more common for participants with graduate studies to mention genetic testing and use terms like DNA and chromosomes, although there was at least one reference to DNA in each education level except those with less than a high school degree. On the other hand, no participants with graduate degrees talked about genetics as being more generally in the blood, while participants in all other education levels, including those with less than a high school degree did.

Examples of how participants used these terms can be seen in the following quotes.

When asked what they think of when hearing the word “genetics”, a participant with graduate-level education replied,

“I think of chromosomes, I think about what we inherit from our father, our mother. I think of DNA. I think about analysis, where they can say specifically if you have – how your chromosomes are, in a chain. In the DNA chain. And all of the studies and analysis that they can do now that they couldn’t do before.” (P101, age 44, Dominican Republic)

“Pienso en los cromosomas, pienso en lo que heredamos de nuestro padre, nuestra madre. Pienso en el DNA. Pienso en análisis, en donde te pueden decir en específico si tienes -- tus cromosomas cómo están, en una cadena. En la cadena del DNA. Y todo de los estudios y análisis que se pueden hacer a hora que antes no se podían hacer.” (P101, age 44, Dominican Republic)

Meanwhile a participant with less than a high school education answered this way,

“No, what’s in your genes that – that sometimes you carry in your blood and all that. But who knows? The truth is – I don’t exactly know if that’s real.”  
(P214, age 33, Guatemala)

“No pues, que viene en sus genes que -- que a veces uno dice lo trae en la sangre y todo eso. Pero ve a saber. La verdad esta -- no sé exactamente si eso es real.”  
(P214, age 33, Guatemala)

### *Uncertainty regarding genetic knowledge*

Despite participants’ ability to discuss conditions they view as hereditary in their families or in the general population, many did struggle when asked what they think of when they think of genetics or how to explain genetics to another person. Some were unable to provide any sort of answer while others who did give an answer also said they did not know. Although many participants demonstrated decent familiarity with genetic concepts, they seemed generally insecure in their genetic knowledge. This theme arose somewhat inversely to descriptions of genetic testing and mention of DNA and chromosomes in that participants with lower levels of education were more likely to cite an inability to describe genetics.

When asked to say what else they associate with the word “genetics,” two participants with a high school degree answered as follows:

“What words come to mind? Genetics. Nothing.” (P104, age 47, Argentina)

“¿Qué palabras se me vienen a la mente? Genético. Nada.” (P104, age 47, Argentina)

On the other hand, even participants with graduate degrees expressed uncertainty despite giving an answer.

“The most colloquial way that I would put it is like...you’re a miniature version... well for a child... you’re a version, a mixed copy of your parents with a ... Yes a mixed copy of what your parents are, in what they are... I don’t know how to explain, genes. A lot of major characteristics of your body.” (P107, age 36, Colombia)

“La manera más coloquial que pondría, es como... eres una versión en miniatura... bueno, para un niño... es una versión, una copia mezclada de tus padres, con un... sí, es una copia la mezcla de lo que son tus padres, en lo que son... no sé cómo explicar, los genes. Muchas características principales de tu organismo.” (P107, age 36, Colombia)



## **Chapter 4 – Discussion**

This study used systematic and semi-structured qualitative methods to explore the causal attributions of breast and colon cancer and mental models of disease inheritance among unaffected Latina immigrant women in the US. In this work, we did not identify the presence of a cultural consensus model of the relative importance of risk factors for breast or colon cancer in the development of each cancer. “Genes/genetic factors” and “hereditary factors” had the highest average ranking for both cancers. While these were also the most salient freelisted causes or risk factors for breast cancer, “high-fat diet” was the most salient in regard to colon cancer. Significant qualitative themes regarding participants’ causal attributions of the two cancers included the role of genetics and heredity in cancer, the role of the psyche in the development of cancer, the additive nature of risk factors, and the ability to modify one’s risk. In regard to mental models of disease inheritance, participants largely associated “genetics” with family members and spoke more about genetic predisposition to common complex disease than Mendelian genetic diseases. Participants also expressed uncertainty in their genetic knowledge. We did find evidence of an association between education level and use of different genetic terminology.

Importantly, this study adds to the scientific literature in several ways. First, it extends previous work using similar freelisting and ranking techniques to explore causal attributions of breast cancer in various populations including Latina women (Chavez et al., 1995). The present study adds updated understanding to that previous work and also draws from a broader Latina population. It also uses the same methods to explore beliefs about colon cancer in Latinas. Second, whereas a previous study has examined beliefs and knowledge about both breast and colon cancers (Wang et al., 2010), this study

focuses specifically on Latina immigrant women and examines beliefs about these two cancers in the same individuals. Finally, the present study adds to the small but growing body of literature exploring mental models or lay theories of disease inheritance by examining such models in Latina immigrants.

### ***Causal attributions of breast and colon cancer***

One significant finding of this research study was the lack of a cultural consensus model in regard to the relative importance of risk factors for both breast and colon cancer. While this is the first study of which the authors are aware that has used this methodology to attempt to identify a consensus model around risk factors for colon cancer, previous work done in the 1990s in California, did identify the presence of such a cultural consensus model among Latina immigrants in regard to breast cancer (Chavez et al., 1995). Specifically, that study looked at Salvadoran and Mexican immigrant women separately but also found that these two groups together met the analytical criteria of a shared cultural model.

There are various reasons which may explain the failure of this study to identify a single cultural model. To begin, the population in this study was much more diverse than that used in the previous study. Consequently, there may be culturally informed models of breast and colon cancer risk factors at play when studying more strictly defined cultures. For example, the previous study only sampled Salvadoran and Mexican immigrant women while this study included Latina immigrants from 11 different countries. In addition, the work by Chavez, et al. (1995) restricted eligibility to participants without a college degree whereas the present study included women with educational levels ranging from less than high school to graduate degrees. It is

reasonable to consider that cultural consensus models may exist among Latina immigrants who share more similar countries of origin or more similar educational levels. In fact, one qualitative study of Mexican, Cuban, and Puerto Rican women with a personal or family history of breast or ovarian cancer found that all three groups mentioned similar causes of cancer, but that the relative importance given to these factors was different among groups, with Puerto Rican women emphasizing lifestyle factors over family history (Vadaparampil, McIntyre, & Quinn, 2010).

Furthermore, the study by Chavez and his colleagues (1995) was done over 20 years ago. Consequently, it is possible that scientific discoveries, such as the discovery of the BRCA1 and BRCA2 breast cancer susceptibility genes, changes in sources of health information due to the proliferation of the internet and social networks, and cultural changes over time have made it so that ideas about risk factors for breast cancer are no longer culturally-informed in Latina immigrants to the US. It may be the case that these beliefs are now more individually-informed as evidenced by participants who referenced experiences of friends and relatives who had had cancer while completing the ranking of possible risk factors. Evidence of this temporal shift in causal attributions may be seen in the ranking and salience of “a blow or hit to the breast” as a risk factor for breast cancer. In the study by Chavez et al (1995), this item was ranked first and second by Mexican and Salvadoran immigrant women respectively. Furthermore, it was the most frequently freelisted risk factor for breast cancer in these populations with 64% of Mexican participants and 29% of Salvadoran participants mentioning it (Chavez et al., 1995). Conversely, in this study, only 18% of participants freelisted “a hard hit or blow to the breast” as a risk factor for breast cancer, and overall, it had an average ranking of

24 out of 28 factors. The ranking and salience of this item 20 years ago compared to now may be indicative of the ways that these causal beliefs are changing.

The lack of a cultural consensus model in this population in regard to breast and colon cancer risk factors tells us that there is not an underlying Latino immigrant culture that informs this population's beliefs in these domains. Nevertheless, this does not mean that Latinos do not have a shared culture, as is generally accepted (Arredondo, Gallardo-Cooper, Delgado-Romero, & Zapata, 2014; Lawton, Gerdes, Haack, & Schneider, 2014; Penchaszadeh, 2001).

#### IMPORTANCE OF GENETICS AND HEREDITY

The importance ascribed to genetics and heredity in the development of breast cancer is an important specific difference between the findings of Chavez and others in the 1990s and the findings of this study. In the study by Chavez and colleagues, this factor was termed “family history” and was ranked 1<sup>st</sup> for breast cancer risk by US-born women of Mexican descent, non-Hispanic white women, and physicians but was ranked 7<sup>th</sup> and 20<sup>th</sup> by Mexican and Salvadoran immigrant women, respectively. Meanwhile, in our study “genes/genetic factors” was the highest ranked factor for breast cancer. The present study also showed that Latina immigrants gave weight to these risk factors for colon cancer. Given that BRCA 1 and 2 were both discovered after the interviews conducted by Chavez and his colleagues and the general explosion of genetic knowledge over the past 20 years, it is somewhat unsurprising that Latina immigrants have incorporated genetics and heredity into their causal attributions of breast and colon cancer. Nevertheless, it is striking that this is a significant shift from the Latina immigrant model found 20 years ago towards a model that may be more similar to that of

non-Hispanic whites and even physicians. In addition, these results show that the information about the role of genetics and heredity in the development of breast and colon cancer has reached this sector of the population.

Furthermore, this finding is consistent with other studies in this area, which have shown that respondents tend to consider heredity to be the most important factor for the development of breast and colon cancer. Specifically, one web-based study of 439 unaffected women (11% Hispanic) which used the Revised Illness Perceptions Questionnaire, found that heredity was ranked as the most important causal factor for both breast and colon cancer and that 84.4% of participants and 78.5% of all participants agreed or strongly agreed with heredity as a cause of breast and colon cancer respectively (Wang et al., 2010). Subgroup analysis by ethnicity showed that Hispanics fell between black and white respondents with 75% of Hispanic respondents agreeing or strongly agreeing with heredity as a cause of breast cancer. However, Hispanics had the highest level of endorsement of heredity as a cause of colon cancer, with 85% of Hispanic participants endorsing this factor. On the other hand, a study which used qualitative interviews including freelist to assess participants' knowledge, beliefs and screening preferences in regard to colorectal cancer found that only three of ten white and three of ten African American participants mentioned family history as a risk factor for colon cancer and none of the ten Hispanic participants mentioned it as a risk factor (Shokar, Vernon, & Weller, 2005). However, this study was published over 11 years ago, and may not be as relevant to the current Latino perspective. Meanwhile, a more recent Australian case-control of 1,109 women with breast cancer and 1,633 unaffected women,

found that unaffected women most commonly (77.6%) attributed breast cancer to familial or inherited factors (Thomson et al., 2014).

Despite the evidence that Latinas do see genetics or heredity as a cause of breast and colon cancer, a recent review article cited various studies which have shown that Latinas have less awareness of and knowledge about genetic testing for hereditary breast cancer when compared to other racial and ethnic groups (Lynce et al., 2016). This was also reflected in our study with only a few highly educated participants mentioning genetic testing. Consequently, many Latinas may believe that genetics and heredity play a role in breast and colon cancer but may not be aware of their ability to be tested or take action if at increased risk.

#### LACK OF GENETIC FATALISM

Despite their belief in genetics/heredity as a cause of breast and colon cancer, our study found little to no evidence of genetic fatalism in this population. On the contrary, participants routinely discussed ways in which one could lower their risk of both types of cancer, even in the face of a genetic predisposition. Most often this was in regard to various positive health habits such as eating healthy and exercising. This is encouraging given that researchers and public health workers have been concerned that increasing beliefs in genetic causes of illness will make individuals feel that any preventive actions are futile leading to poorer health behaviors and poorer health outcomes (Bates et al., 2003). In fact, some studies have shown that when a disease is perceived as being genetic in nature, it is seen as more threatening and less modifiable (Senior, Marteau, & Peters, 1999). Other studies have shown increased cancer fatalism in the Latino population regardless of genetic beliefs. Specifically, one study of responses from 104

Asians, 496 Hispanics, and 4,103 whites to the 2005 Health Information National Trends Survey found that overall Asians and Hispanics are significantly more likely to make fatalistic causal attributions of colon cancer than are whites (Jun & Oh, 2013). This was demonstrated in their increased odds of agreeing that “there is not much you can do to lower the chances of getting colon cancer”, that “everything causes colon cancer”, and that “cancer is not often caused by a person’s behavior or lifestyle.” However, Hispanics were less likely than either Asians or whites to agree that “there is no way to slow down or disrupt colon cancer.” Although the authors do not comment on this seeming contradiction, these results may indicate that Hispanics tend to believe that an individual’s actions do not cause colon cancer but an individuals’ actions can prevent colon cancer. This is similar to our finding that participants had heard that breast-feeding helped to prevent breast cancer but they did not necessarily believe that the converse was also true, that not breast-feeding would increase a woman’s risk of having breast cancer.

Ours is not the first study to suggest that many individuals understand or believe in gene-environment interactions at some level, allowing them to believe in genetic predispositions to disease while still recognizing the value of positive health behaviors as a way of preventing or lessening the effects of the condition. For instance, as mentioned in the introduction, one study used the idea of a “gene for heart disease” to explore public perceptions of medical genetics (Bates et al., 2003). Researchers found that the majority of individuals saw a “gene for heart disease” to mean that both environmental and genetic factors play a role in the disease and that this gene determines a heightened risk but not an absolute certainty of developing heart disease. However, there were minority groups of participants who did believe that “a gene for heart disease” meant that genetics does

not contribute to the disease or who ascribed to genetic absolutism and interpreted this phrase to mean that only genetics contributed. Consequently, the authors concluded that genetic fatalism is not as predominant as some had thought or feared but that there are individuals who may have a fatalistic view of genetics. Another study of 13 focus groups comprised of 106 diverse participants from low-income, medically underserved communities in Cleveland explored the meanings that individuals in these communities ascribe to genetic concepts including gene-environment interactions and their implications for addressing health disparities (Goldenberg et al., 2013). In this study, the researchers again found that participants attributed poor health to various factors, including environmental triggers of genetic traits, and supported the idea of considering genes and environment together in addressing health disparities.

#### ETHNICALLY-BASED RISK PERCEPTIONS

Interestingly, in this study, participants who cited a specific race as being at higher risk of breast or colon cancer, nearly always stated the belief that Latina women were at higher risk of developing breast cancer and, to a lesser extent, colon cancer than white women even though this is objectively not true. According to the American Cancer Society, breast cancer incidence rate in Latinas is 26% lower than in non-Hispanic white women (American Cancer Society, 2014). What is true, is that Latinas are more likely to be diagnosed with breast cancer beyond the earliest stages when compared with non-Hispanic white women even when controlling for age, socioeconomic status, and method of detection. Furthermore, Latina women are more likely to be diagnosed with tumors that are more difficult to treat due to being larger and hormone receptor negative, and even considering age, stage, and tumor characteristics, Latinas are more likely to die from



breast cancer than non-Hispanic white women. Similarly, the colorectal cancer rate among Latinas is 16% lower than among non-Hispanic white women, but again, Latinos are more likely to be diagnosed with distant-stage colorectal cancer than non-Hispanic whites (American Cancer Society, 2014). It is possible that participants in our study have heard the message that they are more likely to be diagnosed with more advanced breast or colon cancer but have misinterpreted this to mean that they are actually at higher risk of developing the disease. On the other hand, it is also possible that exposure to advanced disease or greater fatality from breast cancer has influenced their risk perceptions to make it seem to them that Latinas are at greater risk of the condition.

Some previous studies have shown that Latinas have a lower perceived risk of breast cancer than African American or non-Hispanic white women (Orom, Kiviniemi, Shaver, Ross, & Underwood, 2013), but another study has shown that they still tend to overestimate their absolute breast cancer risk (Graves et al., 2008). Risk perceptions are a complicated field of study with various nuances to their measurement and interpretation that are beyond the scope of this work. Nevertheless, in each of the studies mentioned above, risk perceptions were measured as the individual's personal perceived risk of developing breast cancer as opposed to the general relative risk of one race over another, so it is difficult to say how these previous studies fit with the findings of the present study. In fact, it is difficult to relate our findings to the risk perception literature in general since comparative risk perceptions are usually measured as the risk an individual perceives for him or herself relative to that of another similar person. Our data do not speak to this individual level of risk perception. However, the literature shows that risk perceptions do play a role in health behaviors. A review on cancer risk perceptions (Klein

& Stefanek, 2007) states that studies show that higher risk perceptions of breast cancer predict use of mammography screening. Consequently, there is hope that the perception among Latinas that they are at higher risk of breast cancer than similar women of other races and ethnicities may lead them to utilize mammography screening. On the other hand, the same review points out that higher risk perceptions are also anxiety provoking, which may lead some individuals to avoid the risk of receiving a cancer diagnosis by avoiding screening. Finally, the review also recognizes that there is some evidence of, but little research into, ethnic and cultural differences in risk perceptions and possibly in their correlations with health behaviors (Klein & Stefanek, 2007). Research into Latina's perceived risk of breast cancer and association with utilization of screening is needed.

#### SIMILARITY TO CAUSAL ATTRIBUTIONS IN OTHER POPULATIONS

Although different from the findings among Latinas 20 years ago, the causal attributions of breast and colon cancer identified in Latina immigrants in this study are similar to such causal attributions found in other populations in recent studies. For example, as mentioned above, the study by Wang et al (2010) found that family history was the highest ranked cause of both breast and colon cancer in their sample and that it was endorsed as a cause of both cancers by nearly 80% of respondents. Similarly, this study also found that significantly more participants endorsed diet or eating habits as a cause of colon cancer versus breast cancer. While a direct comparison with the findings of our study is impossible given that our study included multiple diet-related items, our participants ranked "a high-fat diet" 4<sup>th</sup> in regard to colon cancer, and it was the most salient freelisted item. In contrast, it was ranked 12<sup>th</sup> in regard to breast cancer and was freelisted by only one respondent. Finally, Wang and her colleagues (2010) note that

although previous studies had shown that only white women attributed colon cancer to stress or worry, Latina respondents were actually more likely to endorse stress or worry as a cause of both breast and colon cancer. This is in line with our finding that the role of stress and the psyche in the development of cancer was a strong theme across interviews. However, it should be noted that participants ranked “stress” towards the middle of the list for both breast and colon cancer, and “negative or unresolved emotions” was ranked around the bottom third in both cancers.

Furthermore, the case-control study done by Thomson et al (2014) in Australian women found that unaffected women most commonly cited familial factors such as family history or genetics as the cause of breast cancer. In open-ended responses, very similar to our study, these women often spoke of this in terms of an underlying biological fault which lay dormant until ‘triggered’ by something else such as stress or an environmental exposure. Also similar to our findings, these women commonly cited general poor diet and environmental factors such as ‘pollution’, ‘toxins’, ‘chemicals’, and food additives like preservatives and hormones. These authors point out that in their study biomedically-accepted physiological risk factors such as current age and age at menarche were infrequently mentioned by either cases or controls. In our study, only one participant freelisted age as a risk factor without being given category prompts and no participant mentioned age at menarche or menopause. Thomson and colleagues conclude that there are some significant discordances between the causal attributions of their respondents and the causes recognized by the medical community. Nevertheless, the causal attributions of the unaffected Australian women are largely similar to those of Latina immigrants in the US as identified in our study.

The implication from these studies in relation to our findings is that the current-day breast and colon cancer causal attributions of Latina immigrants may not be very different from those of the general US patient population. A qualitative interview study of 50 clinicians and 40 pregnant Latina patients being offered amniocentesis (Hunt & de Voogd, 2005) found that over half of clinicians felt that Hispanic or Latina patients were the most likely to refuse amniocentesis and attributed this to the perceived cultural traits of religiousness, fatalism, family-centeredness, fear, and superstition. Nevertheless, the authors found that 60% of their participants accepted amniocentesis, which fell within the reported acceptance rates of the general population (57-77%). Despite the Latinas' choices fitting with the general population, the authors also found differences in the ways in which clinicians treated Latina patients and provided information to them based on these cultural stereotypes. The authors conclude that there exists a "myth of the cultural other" leading clinicians to inappropriately treat Latina patients differently (Hunt & de Voogd, 2005). Given that Latina breast and colon cancer causal attributions as identified in our study do not differ greatly from those reported in the literature of the general US population, it is possible that healthcare providers hold a similar myth, thinking Latinas' beliefs are vastly different from those of other patients and of the medical community.

This may relate to the cancer health disparities seen in Latina patients in regard to stage at diagnosis of breast or colon cancer and lower than predicted use of genetic testing for hereditary breast and ovarian cancer. The fact that the causal attributions found in our study may not differ greatly from those of other cultures would seem to suggest that differences in causal attributions do not account for these disparities. Rather, these disparities may be due to systemic barriers such as language, financial situation,

insurance coverage, and access to care. An additional systemic barrier may be the way in which providers treat Latina patients if they are interacting with them based on unfounded cultural stereotypes as seen by Hunt and Voogd (2005).

It is also possible that cultural factors other than culturally informed causal attributions are at play. For instance, in a study of 53 Mexican, Puerto Rican, and Cuban women with medical histories that warranted referral to a genetics professional for risk assessment for hereditary breast and ovarian cancer (Vadaparampil et al., 2010), 6 women reported that a doctor had suggested a genetics consultation. However, none of the women had followed up on this recommendation. Three of the women cited financial reasons for not seeing a genetics professional while two mentioned that there was no follow up discussion on the part of the provider. These reasons highlight potential systemic and cultural barriers. It is possible that providers did not follow up with their Latina patients regarding a genetics visit because they believed that Latinas are not likely to undergo genetic testing. However, it is also possible that the providers discussed a genetics appointment in the same way as they would with any patient, but the lack of follow up was interpreted by Latina patients as a lack of importance. This cultural phenomenon has been seen previously in Latinas undergoing prenatal genetic testing (Browner, Preloran, Casado, Bass, & Walker, 2003). It has also been suggested that in coming from a less individualistic and more patriarchal culture, Latino patients expect more direction from healthcare providers (Penchaszadeh, 2001). While the shift towards shared decision-making in healthcare has many benefits, its application must be patient-centered, taking into account cultural interpretations of the offering of a choice versus the prescription of an action. In sum, this means that Latina patients may require more in-

depth or repeated discussion of a genetics referral in order for them to grasp its potential significance for their health and make a more informed decision as to whether or not to follow-up.

Similar to other studies, our study showed that this group of Latina immigrants was generally less aware of colon cancer than breast cancer. In fact, this has been described previously in the literature in this and other populations. In a study using data from 12,035 respondents to the 1992 National Health Interview Survey Cancer control Supplement (Breslow, Sorkin, Frey, & Kessler, 1997), researchers compared the percentage of respondents who identified age as a risk factor across different cancer types. Among women surveyed, the authors found that more white, black, and Hispanic women identified age as a risk factor for breast cancer than for colon cancer despite age being a significant risk factor for both cancers. Specifically among Hispanic women, 22.4% mentioned age as a risk factor for breast cancer compared to 15.0% who mentioned it as a risk factor for colon cancer. Similarly, across demographics, this study showed that whereas knowledge regarding survival of breast cancer was relatively high, it was significantly lower for other cancer types, including colon cancer (Breslow et al., 1997). These results could indicate that US women, including Latinas, are generally more aware of and familiar with breast cancer than colon cancer. However, this difference in awareness may be more striking in the Latino population. The previously mentioned qualitative freelist study by Shokar et al (2005) found that in freelist types of cancer, only one-third of Latino participants mentioned colon cancer compared to one-half of African American participants. Furthermore, only diet was listed by more than one Latino participant as a risk factor for colon cancer, while five or six factors were

listed by more than one African American or white participant, respectively. Finally, no Latino participant correctly named a colon cancer screening test (Shokar et al., 2005). Consequently, the results of the present study add to the growing literature on the disparate awareness of colon cancer.

All in all, many of our findings regarding this population's causal attributions of breast and colon cancer are very similar to those reported in recent studies of other populations. However, it is striking how different these causal attributions are from those identified 20 years ago by Chavez and his collaborators (1995). This possible shift in causal attributions towards a model that may be similar to that of the general public has implications for patient-provider interactions as detailed below.

### ***Mental models of disease inheritance***

Similar to the causal attributions of breast and colon cancer, the mental models of disease inheritance described by participants in this study were very much in line with those described in studies in other populations. For example, participants were very familiar and comfortable with the idea of both traits and health conditions running in families in keeping with McAllister and colleague's (2003) idea that all individuals are naïve geneticists and that "some knowledge about the inheritance of physical characteristics, personality and illness is part of family culture." Nevertheless, many participants expressed uncertainty about their understanding of genetics and struggled to articulate how inheritance works or what genetics is, which has also been seen across studies (Henderson & Maguire, 2000; Lanie et al., 2004). Similar to our findings, in the study by Henderson and Maguire (2000) of Welsh undergraduate students, even those participants who went on to give fairly accurate and sometimes detailed explanations of

genetic inheritance often began by stating that they had limited knowledge of genetics. This phenomenon may indicate that the lay public perceives genetics to be a complex field shrouded in mystery and perceives a significant lack of understanding in this area despite many having a working knowledge sufficient for most situations. Lanie et al (2004), recognize the potential benefit of a perceived lack of knowledge and suggest that individuals who do not recognize their misconceptions would likely be the most difficult to educate in a medical genetics encounter.

As mentioned previously, the lack of genetic fatalism and discussion of health behaviors that can modify genetic predisposition seen in this population has also been seen in other populations in the US (Bates et al., 2003; Goldenberg et al., 2013). Another similarity between the genetic models captured in this study and previously described lay models is the discussion of genes as lying dormant and being activated or triggered by some behavior or environmental exposure. Some version of this concept has been described by participants from various populations including Welsh undergraduate students, Australian women, and a racially-diverse sample of individuals living in low-income communities in Cleveland (Goldenberg et al., 2013; Henderson & Maguire, 2000; Thomson et al., 2014). Potentially, this belief that genes need to be activated in order to cause illness mitigates any possible tendency towards genetic fatalism. Ultimately, the models of disease inheritance we found among Latina immigrants are quite similar to those models and beliefs about genetics held by the mainstream lay public in the US. Even some common misconceptions, such as genes being “triggered” by external forces, were shared by this population. This similarity to other models is especially significant in light of the findings from a study of 61 British-Pakistani families referred to genetics



clinics in the UK (Shaw & Hurst, 2008) that found culturally-informed beliefs about genetics that diverged greatly from that of both the medical community and the lay public. For instance, those participants expressed beliefs such as that a child inherits the majority of his or her genetic material from the father and that consanguineous marriage could not cause disease since this practice had been followed for centuries by their ancestors (Shaw & Hurst, 2008). Although Latina immigrants may generally hold similar mental models of disease inheritance as the US lay public it is likely that some other cultural groups do not.

#### THE ROLE OF EDUCATION

We also found that education level may play a role in an individual's model of disease inheritance. Intuitively, this is unsurprising since more time in formal education would likely provide greater exposure to genetics and genetic concepts and would also provide the individual with generally higher literacy, allowing him or her to understand medical and media explanations of genetics more fully. This increased genetic knowledge would be expected to influence an individual's model of disease inheritance. The relationship between higher level of education and increased genetic knowledge has been reported in the literature (Haga et al., 2013). However, there is little to no literature on the actual role of education in models of disease inheritance. Henderson and Maguire (2000) found a range of models of disease inheritance within the sample which consisted entirely of undergraduate students in their first academic week of undergraduate studies. Presumably, these participants all had the same or very similar levels of prior education, yet they demonstrated variety in models of disease inheritance. Though not specific to disease inheritance, a study that investigated the relative importance given to genes,

environment, and personal behavior in various human traits sampled 77 African American and European American individuals between the ages of 18 and 45 divided into 16 focus groups that were uniform by race and sex (Parrott et al., 2003). In this study, the authors compared respondents who reported completing a college level course in biology to those who did not and found significant differences. Specifically, the authors found that those who had taken such a course rated the role of social factors on talents higher and the role of personal behaviors on talents lower than those who had not taken a college biology class. These results do not provide direct insight into genetic models but do suggest that education may play a role in mental models.

#### FIT WITH PREVIOUSLY DESCRIBED MODELS

Henderson and Maguire's (2000) work in mental models of disease inheritance stands out within the literature due to the fact that the authors drew on participants' responses to identify and outline three different mental models of disease inheritance. They termed these models Constitutional, Mendelian, and Molecular and, in that order, their models loosely map onto historical phases of the understanding of genetics with Molecular being the most complex. In addition, they recognized that these models were not mutually exclusive, and some participants ascribed to a model that overlapped two of these models while others could not be classified. Our study was not designed to test for the presence or absence of these specific models, and our analysis focused on overarching themes across participants' models as opposed to classifying individual participants' models into categories. Nevertheless, it is interesting to compare the general themes we identified with the models that Henderson and Maguire propose. The themes we identified best fit with a combination of two of Henderson and Maguire's models, what

they term a Constitutional/Molecular model. Similar to the Constitutional Model, most of our participants were aware of some inherited material but had little to no specific knowledge about its location or function. This can be seen in part by some participants identifying infectious transmission of HIV or hepatitis from mother to baby as similar to genetic inheritance. This could be due to a lack of understanding about what the genetic material really is and how this differs from a virus that can be spread from person-to-person. Along this vein, some participants spoke of things being passed down in families because they are in the blood and did not speak specifically of DNA or chromosomes. On the other hand, some study participants did specifically mention DNA when talking about genetics, which corresponds with Henderson and Maguire's Molecular model. Henderson and Maguire also include in their Molecular model the idea of gene-environment interactions in determining whether or not a disease is manifested in a person. As described previously, this idea was prevalent in our population in discussing genetic models and cancer genetics specifically. Therefore, the themes identified in our population seem most similar to the ideas that would be found in a Constitutional/Molecular model.

### ***Limitations***

Like all studies, this one had several limitations. First, although no study is ever entirely generalizable, the sample in this study tended to be more highly educated than would be expected of the foreign-born Latino population in the United States. A full 50% of participants in this study had a bachelor's degree or higher, while nationally only 12% of this demographic holds a bachelor's degree or higher (Ryan & Bauman, 2016). Even for the geographic region, this sample was highly educated. According to the US Census

Bureau, 20% of foreign-born Hispanics in Montgomery County, Maryland, the county in which the majority of interviews took place, hold a bachelor's degree or higher. Even though the sample did include participants with less education, the overall themes identified may be less relevant to Latina immigrants with lower levels of education. Furthermore, since this population was recruited almost entirely through the NIH research networks, it is possible that these participants are generally more biomedically oriented than other Latina immigrants.

Second, no cultural consensus model was identified regarding the relative importance of the various risk factors for either breast or colon cancer. Although average rankings of each of the ranked items were used to give an overall ranking, the lack of a single model limits the weight that can be given to those rankings. This also led to several items having very similar average rankings, making it difficult to draw firm conclusions about their relative order. Nevertheless, the high salience in freelisting and the high relative average ranking of genetics and hereditary factors in both breast and colon cancer do allow us to conclude that these items were important causal attributions in this population.

Although there were some broad correlations between use of genetic terminology and education level, this study was qualitative in nature and was not designed to be able to identify any statistically significant associations. Consequently, this would be an area for future research.

Finally, the organization of the interview may have primed participants to think in a certain way when discussing their models of genetics. Since the sections discussing breast and colon cancer occurred first, participants were likely in the mindset of cancer

when the discussion turned to genetics, even though the researcher explained that the goal was to think about genetics in general. This may have contributed to participants' tendency to discuss common complex or multifactorial diseases in regard to genetics more than single-gene, Mendelian diseases. As a result, our findings may not represent the full scope of these participants' mental models of disease inheritance.

### ***Practice Implications***

Our findings lend themselves to several practice implications. First, the fact that Latina immigrants seem to be less aware of colon cancer provides an area for education. Healthcare providers and public health advocates need to inform Latina patients about colon cancer, including what it is, the causes, screening mechanisms, and prevention behaviors. Based on our results, it is also important to explain to some individuals that both men and women can get colon cancer.

Second, providers should recognize the strong focus in this population on genetics, stress, and diet as causes of these cancers and keep them in mind when talking with Latina patients. Even more importantly, providers should be aware of the biomedically-endorsed risk factors of each cancer that are not salient in this population. For example, current age and alcohol consumption are breast cancer risk factors which were not emphasized in this population, and age at menarche and age at menopause were not raised as risk factors at all. Similarly, current age was not emphasized as a risk factor for colon cancer and most participants were unaware of the association between type 2 diabetes and colon cancer. This last point is especially poignant for this population, which is disproportionately affected by diabetes (American Cancer Society, 2014). Providers ought to reinforce or take extra care in explaining the basis of these risk factors

within the beliefs already held by these patients. Nevertheless, providers also need to recognize that the causal attributions found in this population are not very different from those previously found in the general lay public. Consequently, providers need not greatly modify their discussions of breast and colon cancer risk factors from that which they would have with other patients beyond taking into account general language barriers, cultural interpretations of non-verbal cues, and education level, as for any patient.

The findings of this study indicate a great opportunity for providers in talking with Latina immigrants since they appear to be very open to behavior modification in order to improve health, especially in areas such as diet. Many participants spoke about different diet items that could affect one's cancer risk and some even mentioned dietary changes they had already made. Providers should not miss the opportunity to reinforce risk-reducing behavior changes and encourage further changes such as in reducing alcohol consumption and increasing physical activity as well as explaining and promoting appropriate cancer screening mechanisms.

Finally, in discussions of genetics, providers should be aware of the existence of lay genetic models in the public in general, but they should also know that many Latinas likely hold genetic beliefs that are more similar to the general non-Hispanic white population than they are different. Providers do not necessarily need to assume lower genetic awareness in this population than would be warranted for any patient.

Furthermore, healthcare professionals should recognize that most people, regardless of education, have some uncertainty regarding their own understanding of genetics and use that uncertainty as an opportunity to fill in important gaps in knowledge. Despite this

insecurity in their own understanding, many participants did have correct ideas in addition to misconceptions. Eliciting a patient's own model of disease inheritance prior to providing education will allow the healthcare professional to identify important areas of education and ways to relate this new information to the patient's existing model. The pervasive idea that genes interact with the environment or behavior should be helpful for providers discussing multifactorial conditions with patients who may be at risk for inherited cancer and cardiovascular syndromes, Alzheimer's, diabetes, obesity, and more. On the other hand, the lack of discussion of purely dominant or recessive conditions, may mean that lay people, including Latinas, will struggle more to understand these types of inheritance and their health implications. While the importance of this information to any patient will depend on their own family's health conditions, it would be necessary to explain in the context of prenatal carrier screening or a family diagnosis of a condition such as cystic fibrosis, Huntington's disease, or achondroplasia.

### ***Future Research***

In addition to suggesting practice implications, our findings highlight several areas of future research. To begin, additional research into awareness of and specifically causal attributions of colon cancer in any population would contribute to the literature. Given the growing evidence that the public is less aware of colon cancer than other cancers, intervention studies on the best way to educate the public about risk factors and screening for colon cancer could inform public health initiatives. In addition, although there is research into the causal attributions of breast and colon cancer, it is important to extend this to the next step of the health behavior models to identify how these attributions influence health behaviors. This research is necessary not only in regard to

Latinas but in the general public as well. Finally, further research into lay theories of disease inheritance as a function of education level are warranted. Specifically, investigation in this area among a sample of Latina immigrants whose education level is more representative of the national Latina immigrant population could further highlight ways in which our findings do or do not represent models held by this population.

### ***Conclusion***

This study found that Latina immigrant women tend to share causal attributions of breast and colon cancer and mental models of disease inheritance that are similar to those of the general public. It extends the literature by building on previous work regarding causal attributions of breast and colon cancer held by Latinas and beginning work in the area of models of disease inheritance in this population. Our findings present data for healthcare providers regarding these health beliefs which can inform their approach to educating patients and suggests that educational approaches to Latina patients do not need to assume different cultural beliefs. This is not to say that they do not require the use of culturally-sensitive language, images, and means of presenting information. Finally, this extension of the existing literature highlights additional areas in which further research could extend our understanding and improve our patient-provider interactions. As the largest minority group in the United States and a rapidly growing sector of the population, we cannot ignore the beliefs of Latino patients and their impact on health outcomes. As shown by this work, we cannot assume that these beliefs are either so similar to nor so different from our own but rather in the true spirit of cultural competence, must keep an open mind and seek to understand each patient as an individual in order to provide the best care.



## **References**

## **APPENDICES**

### ***APPENDIX A – Semi-Structured Interview Guide in English and Spanish***

#### **English Version:**

Interviewer: *Now we are going to start the interview. I'm going to start by asking some general questions about you. Please feel free to ask me if you do not understand any question. Also, remember that you can choose not to answer any question if you would prefer not to answer. If you feel uncomfortable or would like to stop the interview at any point, you can let me know.*

*For these general questions, I have a sheet that you can fill out on your own or we can go through together verbally. How would you prefer to complete this section?*

[Sociodemographic questions and acculturation scale are completed according to the participant's preference]

Interviewer: *Next, I want to ask you some questions about any experiences you have with cancer in your family.*

#### ***Personal and family history of cancer:***

1. Have you ever had cancer?
  - 1.1. If so, what type of cancer?
  - 1.2. At what age was it diagnosed?
  - 1.3. What year was it diagnosed?
2. Has any relative of yours had cancer?
  - 2.1. If so, what is that person(s)'s relationship to you?
  - 2.2. What type(s) of cancer did he or she (they) have?
  - 2.3. Approximately how old was your relative when his or her cancer was diagnosed?
  - 2.4. Approximately how old were you when that cancer was diagnosed?
  - 2.5. What was the outcome of that cancer? (cured? in remission? deceased?)

Interviewer: *Thank you for sharing that information with me. Now, I want to move on to some questions about the causes and risk factors of some specific types of cancer.*

#### ***Freelisting:***

3. Please list everything that you think could cause or increase a person's chance of developing breast cancer. There are no right or wrong answers, but it is helpful if you are as specific as possible.

**3.1.** Could you please tell me more about why you think X increase a person's chance of developing breast cancer?

**3.2.** *For stage I interviews only: Now I'm going to list some categories of causes or risk factors to see if they make you think of anything else that could contribute to the development of breast cancer.*

3.2.1. Lifestyle

3.2.2. Things in the environment or that one is exposed to

3.2.3. Biological or medical factors

3.2.4. Things that one consumes

3.2.5. Having children

3.2.6. Things that can happen to the body

3.2.7. Psychological factors

3.2.8. Demographic factors

- 4.** Please list everything that you think could cause or increase a person's risk of developing colon cancer. There are no right or wrong answers, but it is helpful if you are as specific as possible.

**4.1.** Could you please tell me more about why you think X increase a person's chance of developing colon cancer?

**4.2.** *For stage I interviews only: Now I'm going to list some categories of causes or risk factors to see if they make you think of anything else that could contribute to the development of colon cancer.*

4.2.1. Lifestyle

4.2.2. Things in the environment or that one is exposed to

4.2.3. Biological or medical factors

4.2.4. Things that one consumes

4.2.5. Having children

4.2.6. Things that can happen to the body

4.2.7. Psychological factors

4.2.8. Demographic factors

***Ranking of causes:***

- 5.** Please take these cards, which contain the names of some things, which may cause or increase a person's chance of developing breast cancer. Feel free to look through them and then put them in order starting with what you think plays the largest role in developing breast cancer to what you think plays the smallest role in developing breast cancer. Take your time and feel free to ask me questions if you do not understand any of the items.

- 5.1. Do you think that X is more important in causing breast cancer than Y?
  - 5.2. Do you want to make any changes to your final order?
  - 5.3. Why do you think that A is the most important cause of breast cancer?
  - 5.4. Why do you think that Z is the least important cause of breast cancer?
  - 5.5. Which items here do you think go together? How do they go together?
  - 5.6. In the first part of the interview, you mentioned X, but that cause isn't in these cards. Where would you rank X in this order?
  - 5.7. Does seeing these items make you think of anything else that could contribute to the development of breast cancer? Do you think anything is missing from this list or anything that surprises you?
  - 5.8. Here we have both genetics and heredity. How do you understand those two ideas? Do you see them as the same or different?
  - 5.9. How do you think this order compares with how your mother would rank these items? Would she put them in a similar order or different?
  - 5.10. How does it compare to how your grandmother would rank them?
6. Please take these cards, which contain the names of something, which may cause or increase a person's chance of developing colon cancer. Feel free to look through them and then put them in order starting with what you think plays the biggest role in developing colon cancer to what you think plays the smallest role in developing colon cancer. Take your time and feel free to ask me questions if you do not understand any of the items.
    - 6.1. Do you think that X is more important in causing colon cancer than Y?
    - 6.2. Do you want to make any changes to your final order?
    - 6.3. Why do you think that A is the most important cause of colon cancer?
    - 6.4. Why do you think that Z is the least important cause of colon cancer?
    - 6.5. Which items were the most difficult for you to rank? Why?
    - 6.6. In the first part of the interview, you mentioned X, but that cause isn't in these cards. Where would you rank X in this order?
    - 6.7. Does seeing these items make you think of anything else that could contribute to the development of colon cancer? Do you think anything is missing from this list or anything that surprises you?
    - 6.8. How do you think this order compares with how your mother would rank these items? Would she put them in a similar order or different?
    - 6.9. How does it compare to how your grandmother would rank them?

Interviewer: Now we are on the last part of the interview. In this section, I want to understand more about what you think about genetics. I'm going to ask you some questions about this topic.

***Mental models of disease inheritance:***

7. Could you please tell me all the words that come to your mind when you hear the word genetics? There are no right or wrong answers. I just want to know what you think of.
8. How do you think that genes influence our health?
9. What do you think of when you think of an inherited or genetic condition or disease?
10. Are there any genetic conditions or disease in your family?
  - 10.1. If so, tell me about it.
11. Do you think that an inherited disease is more or less preventable than other diseases? Why?
12. Do you think that an inherited disease is more or less treatable than other disease? Why?
13. Do you think anything else about genes or inheritance that you would like to share?

***Questions about previous contact with other participants:***

14. Have you spoken with any other woman who has already participated in this study?
  - 14.1. If so, did she share with you any print resources she was given after the interview?

Interviewer: *This concludes our interview. Thank you for your time and for contributing to this study.*

**Spanish Version:**

Entrevistadora: *Ahora vamos a comenzar la entrevista. Voy a empezar haciéndote unas preguntas generales. Por favor, no dude en preguntarme si no entiende alguna pregunta. Además, recuerde que puede decidir no contestar cualquier pregunta que no desea contestar. Si se siente incómoda o desea terminar la entrevista en cualquier momento, me puede avisar.*

*Para estas preguntas generales, tengo una hoja que puede llenar a solas o podemos hacerlo juntas verbalmente. ¿Cómo preferiría completar esta sección?*

[Sociodemographic questions and acculturation scale are completed according to the participant's preference]

Entrevistadora: *Ahora, quisiera hacerle unas preguntas acerca de cualquier experiencia que tiene con cáncer en su familia.*

***Personal and family history of cancer:***

1. ¿Ha tenido usted cáncer?
  - 1.1. En caso de sí, que tipo de cáncer?

- 1.2. A que edad fue diagnosticado?
- 1.3. En que año fue diagnosticado?
- 2. ¿Algún pariente suyo ha tenido cáncer alguna vez?
  - 2.1. En caso de sí, cual es su relación con esa persona(s)?
  - 2.2. Que tipo(s) de cáncer tuvo(tuvieron)?
  - 2.3. Aproximadamente a que edad le fue diagnosticado?
  - 2.4. Más o menos cuantos años tuvo usted cuando le fue diagnosticado?
  - 2.5. Cual fue el resultado de ese cáncer? (se curó, se murió, está en remisión?)

Entrevistadora: *Gracias por compartir esta información conmigo. Ahora quisiera pasar a preguntas acerca de las causas y factores de riesgo de dos tipos específicos de cáncer.*

***Freelisting:***

- 3. Por favor, enumere (puede nombrar), todas las cosas que piensa que puede causar cáncer de mama o aumentar la probabilidad de desarrollar el cáncer de mama en una persona. No hay respuestas correctas ni equivocadas, pero ayuda si puede ser lo más específico posible en sus respuestas.
  - 3.1. Por favor, me puede decir porque cree que X aumenta el riesgo de desarrollar el cáncer de mama?
  - 3.2. *For stage I interviews only: Ahora voy a mencionarle unas categorias de factores de riesgo para ver si se le ocurre algo más que puede contribuir al desarrollo del cancer de seno.*
    - 3.2.1. Estilo de Vida
    - 3.2.2. Cosas del medio ambiente o a que uno está expuesto
    - 3.2.3. Factores biológicos o médicos
    - 3.2.4. Cosas que uno consume
    - 3.2.5. Tener hijos
    - 3.2.6. Algo que puede pasar al cuerpo
    - 3.2.7. Factores psicológicos
    - 3.2.8. Factores demográficos
- 4. Por favor, enumere (nombrar), todas las cosas que piensa que puede causar cáncer de colon o aumentar la probabilidad de desarrollar el cáncer de colon en una persona. No hay respuestas correctas ni equivocadas, pero ayuda si puede ser lo más específico posible en sus respuestas.
  - 4.1. Por favor, me puede decir porque cree que X aumenta el riesgo de desarrollar el cáncer de colon?
  - 4.2. *For stage I interviews only: Ahora voy a mencionarle unas categorias de factores de riesgo para ver si se le ocurre algo más que puede contribuir al desarrollo del cancer de colon.*
    - 4.2.1. Estilo de Vida

- 4.2.2. Cosas del medio ambiente o a que uno está expuesto
- 4.2.3. Factores biológicos o médicos
- 4.2.4. Cosas que uno consume
- 4.2.5. Tener hijos
- 4.2.6. Algo que puede pasar al cuerpo
- 4.2.7. Factores psicológicos
- 4.2.8. Factores demográficos

***Ranking of causes:***

5. Por favor, tome estas tarjetas que contienen los nombres de algunas cosas que pueden causar o aumentar el riesgo de desarrollar el cáncer de mama en una persona. Tome su tiempo en leerlas y después ponerlas en orden empezando con la cosa que usted considere que tiene el mayor rol en el desarrollo del cáncer de mama hasta la cosa que usted considere que tiene el menor rol en el desarrollo del cáncer de mama. Tome su tiempo y no dude en hacerme cualquier pregunta si no entiende alguna de las palabras.
  - 5.1. ¿Usted cree que X es más importante en causar el cáncer de mama que Y?
  - 5.2. ¿Usted desea cambiar algo de su orden final?
  - 5.3. ¿Por qué considera que A es la causa más importante del cáncer de mama?
  - 5.4. ¿Por qué considera que Z es la causa menos importante del cáncer de mama?
  - 5.5. ¿Cuáles causas escritas aquí considera usted que van juntas? Cómo van juntas?
  - 5.6. En la primera parte de la entrevista, usted mencionó X, pero esa causa no está en estas tarjetas. ¿Dónde considera usted que entra X en este orden?
  - 5.7. Ver estas cosas le hace pensar en algo más que puede contribuir? Le parece que hay algo que falta o algo que le sorprende?
  - 5.8. Aquí hay factores hereditarios y factores genéticos. Como entiende estas dos ideas? Las ve iguales o distintas?
  - 5.9. Cómo cree usted que este orden de las causas de cáncer de mama se comparan con la manera en que su mamá las ordenaría? ¿Cómo sería similar o diferente?
  - 5.10. ¿Cómo se compara con la manera en que su abuela las ordenaría?
6. Por favor, tome estas tarjetas que contienen los nombres de algunas cosas que pueden causar o aumentar el riesgo de desarrollar el cáncer de colon en una persona. Tome su tiempo en leerlas y después ponerlas en orden empezando con la cosa que usted considera que tiene el mayor rol en el desarrollo del cáncer de colon hasta la cosa que usted considera que tiene el menor rol en el desarrollo del cáncer de colon. Tome su tiempo y no dude en hacerme cualquier pregunta si no entiende alguna de las palabras.
  - 6.1. ¿Usted cree que X es más importante en causar el cáncer de colon que Y?

- 6.2. ¿Usted desea cambiar algo de su orden final?
- 6.3. ¿Por qué considera que A es la causa más importante del cáncer de colon?
- 6.4. ¿Por qué considera que Z es la causa menos importante del cáncer de colon?
- 6.5. ¿Cuales causas escritas aquí considera usted que van juntas? Cómo van juntas?
  - 6.5.1. Son parecidos? Trabajan en conjunto?
- 6.6. En la primera parte de la entrevista, usted mencionó X, pero esa causa no está en estas tarjetas. ¿Dónde considera usted que entra X en este orden?
- 6.7. Ver estas cosas le hace pensar en algo más que puede contribuir? Le parece que hay algo que falta o algo que le sorprende?
- 6.8. Cómo cree usted que este orden de las causas de cáncer de colon se comparan con la manera en que su mamá las ordenaría? ¿Cómo sería similar o diferente?
- 6.9. ¿Cómo se compara con la manera en que su abuela las ordenaría?

Entrevistadora: *Ahora vamos a la última parte de la entrevista. En esta sección, quisiera entender más acerca de que piensa usted de la genética. Le voy a hacer algunas preguntas sobre este tema.*

***Mental models of disease inheritance:***

7. Me puede decir todas las palabras que se le vienen a la mente cuando usted escucha la palabra, genética? Igual que antes, no hay respuestas correctas ni equivocadas. Solo quiero saber lo que se le viene a la mente.
8. ¿Cómo cree usted que los genes influyen en la salud de las personas? No me interesa una respuesta “correcta” solo como usted piensa.
9. Que hacen los genes
10. Si tuviera que explicar la genética a una amiga, como lo haría?
11. ¿En que piensa cuando piensa en una condición o enfermedad genética o hereditaria?
12. ¿Hay alguna enfermedad o condición genética en su familia?
  - 12.1. En caso de sí, cuénteme más al respecto.
13. ¿Usted considera que una enfermedad hereditaria es más o menos prevenible que otras enfermedades? Por qué?
14. ¿Usted considera que una enfermedad hereditaria es más o menos tratable que otras enfermedades? ¿Por qué?
15. ¿Usted tiene algún otro pensamiento o comentario de los genes o la herencia que le gustaría compartir?

***Questions about previous contact with other participants:***

16. ¿Ha hablado con otra mujer que ha participado en este proyecto
  - 16.1. En caso de sí, ¿ella le enseñó alguna hoja de información que se le dio después de la entrevista?

Entrevistadora: *Con esto se concluye la entrevista. Gracias por su tiempo y por contribuir a este proyecto.*



**APPENDIX B – Background questionnaire in Spanish and English**

Participant ID Number: \_\_\_\_\_

**Background questionnaire**

1. How old are you? \_\_\_\_\_

2. In which country were you born? \_\_\_\_\_

3. At what age did you immigrate to the United States? \_\_\_\_\_

4. How long have you lived in the United States? \_\_\_\_\_

5. What is the highest level of education you completed (circle one)?

1	2	3	4	5	6	7	8	9	10	11	12	Graduated from high school	Some college	Two-year college degree	Four-year college degree	Post- graduate studies
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6. In general, what language(s) do you read and speak (circle one)?

1	2	3	4	5
Only Spanish	Spanish better than English	Both equally	English better than Spanish	Only English

7. What language(s) do you usually speak at home (circle one)?

1	2	3	4	5
Only Spanish	More Spanish than English	Both equally	More English than Spanish	Only English

8. In what language do you usually think?

1	2	3	4	5
Only Spanish	More Spanish than English	Both equally	More English than Spanish	Only English

9. What language(s) do you usually speak with your friends?

1	2	3	4	5
Only Spanish	More Spanish than English	Both equally	More English than Spanish	Only English

Do you speak any other languages? If so, which languages?

Número de Identificación del participante: \_\_\_\_\_

**Cuestionario de antecedentes**

1. ¿Cuántos años tienes? \_\_\_\_\_
2. ¿Dónde naciste? \_\_\_\_\_
3. ¿A qué edad viniste a vivir en los Estados Unidos? \_\_\_\_\_
4. ¿Por cuántos años has vivido en los Estados Unidos? \_\_\_\_\_
5. ¿Cuál es el nivel más alto de educación que has completado (marca uno)?

1	2	3	4	5	6	7	8	9	10	11	12	Bachillerat o	Algo de universi dad	Título universita rio de dos años	Título universitari o de cuatro años	Estudios de Posgrado
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6. ¿Por lo general, qué idioma(s) hablas y lees (marca uno)?

1	2	3	4	5
Solo español	Español mejor que inglés	Ambos por igual	Inglés mejor que español	Solo inglés

7. ¿Por lo general, en qué idioma(s) hablas en tu casa (marca uno)?

1	2	3	4	5
Solo español	Más español que inglés	Ambos por igual	Más inglés que español	Solo inglés

8. ¿Por lo general, en qué idioma piensas?

1	2	3	4	5
Solo español	Más español que inglés	Ambos por igual	Más inglés que español	Solo inglés

9. ¿Por lo general, en qué idioma(s) hablas con tus amigos?

1	2	3	4	5
Solo español	Más español que inglés	Ambos por igual	Más inglés que español	Solo inglés

¿Hablas otros idiomas? Si es así, ¿cuál(es) idioma(s)?

***APPENDIX C – Interview Summary Sheet***

Participant ID Number: \_\_\_\_\_

Date of interview: \_\_\_\_\_

Interview location: \_\_\_\_\_

Interview start time: \_\_\_\_\_ Interview end time: \_\_\_\_\_

Context of interview (setting, mood, unique situations):

Adverse events?

Interview question(s) most responsive to:

Interview question(s) least responsive to:

Overall impressions of interview (verbal/nonverbal):

Categories or major themes in interview:

New or different information (from previous interviews):

Suggestions for subsequent interviewees:

## ***APPENDIX D – Resources for Participants in English and Spanish***

### **What is breast cancer?**

Breast cancer is a growth in the breast that should not be there and can cause health problems.

### **How common is breast cancer?**

1 in 10 Latina women will develop breast cancer sometime in her life. Latina women are more likely:

- To get breast cancer at a younger age
- To die from breast cancer if they get it

### **What causes breast cancer?**

There is rarely one cause of cancer. Instead, there are many factors that play a role. These are called **risk factors**. Some risk factors you can change and some you can't.

### **Who can I talk to if I'm worried about breast cancer?**

You should talk to your doctor if you are worried about your risk of getting breast cancer. Your doctor can:

- Recommend and explain a screening test based on your age and history
- Assess if there is any hereditary risk in your family
- Refer you to a genetic counselor if necessary

For more information about breast cancer risk and prevention:

- The National Cancer Institute:  
<http://www.cancer.gov/espanol/tipos/seno>
- The American Cancer Society  
<http://www.cancer.org/espanol/cancer/cancerdeseno/>

For free or low cost mammogram call:

- Montgomery County Women's Cancer Control Program **240-777-1750**
- Prince George's County Health Department **301-883-3525**
- Other counties **1-800-477-9774**

### **What you need to know about Breast Cancer**



### **A Latina's guide to risk and prevention**

Sources: The American Cancer Society (Cancer.org), the National Cancer Institute (Cancer.gov), and the National Comprehensive Cancer Network (NCCN.org)

## What are lifestyle or behavior risk factors?

- Drinking alcohol – raises your risk of breast cancer.
- Low physical activity – women who do regular exercise have lower risk.
- Overweight – being overweight or obese (BMI>25) raises your risk.
- Not having children or having your first child after age 30 – raises your risk of getting breast cancer.



## What are other breast cancer risk factors?

- Gender – women have a higher risk of breast cancer than men.
- Age – risk increases with age.
- Family history – having a mother, grandmother, sister or aunt with breast cancer.
- Genetic changes – changes in some genes increase breast cancer risk.

## How can I prevent breast cancer?

You can lower your risk of breast cancer by changing the risk factors that you can control. For example:

- **Avoid alcohol** or only have 1 drink per day.
- **Lose weight** if you are overweight or obese.
- **Exercise** – try to walk 1.25 to 2.5 hours per week.



## How can I get screened?

**Screening** is looking for cancer early before it causes symptoms. Finding cancer early often makes it easier to treat. The main screening test for breast cancer is called a **mammogram** and is an x-ray of the breast.

- If you are between 45 and 54 you should get a mammogram yearly.
- If you are younger than 45 or older than 54 you should talk to your doctor about screening.

## More about Genetic risk factors

In rare cases, breast cancer can run in families. Here are some signs that breast cancer might run in your family:

- Multiple relatives with breast, ovarian, or prostate cancer
- You or a relative with breast, ovarian, or prostate cancer before age 50
- A male relative with breast cancer
- You or a relative with breast cancer in both breasts

## What is my breast cancer risk?

Check the risk factors you have to see your breast cancer risk. Remember to share them with your doctor when you talk about screening.

- ☐ I am a woman.
- ☐ I am over age 40.
- ☐ I have more than 1 drink of alcohol per day.
- ☐ I have 1 or more of the genetic risk factors listed above.
- ☐ I am overweight or obese.
- ☐ I do little physical activity.
- ☐ I had my first child after age 30.

## ¿Qué es el cáncer de mama?

El cáncer de mama es un crecimiento en los senos que no debería estar ahí y que puede causar problemas de salud.

## ¿Qué tan común es el cáncer de mama?

Una de cada diez mujeres latinas desarrollará cáncer de mama en algún momento de su vida. Las mujeres latinas tienen más probabilidades de:

- Contrar cáncer de mama a temprana edad.
- Morir de cáncer de mama si lo padecen.

## ¿Qué causa el cáncer de mama?

Pocas veces existe solo una causa del cáncer. Más bien, son muchos los factores que entran en juego. Se les conoce como **factores de riesgo**. Usted puede cambiar algunos factores de riesgo; otros no.

## ¿Con quién puedo hablar si me preocupa el cáncer de mama?

Debe hablar con su médico si le preocupa el riesgo de tener cáncer de mama. Su médico puede:

- Recomendar y explicar una prueba de detección en función de su edad y sus antecedentes.
- Evaluar si hay algún riesgo hereditario en su familia.
- Remitirla a un consejero genético si es necesario.

Para obtener más información sobre el riesgo y la prevención del cáncer de mama:

- The National Cancer Institute:  
<http://www.cancer.gov/espanol/tipos/seno>
- The American Cancer Society  
<http://www.cancer.org/espanol/cancer>

Para una mamografía gratis o económica llame al:

- Programa para Control del Cáncer en la Mujer del Condado de Montgomery **240-777-1750**
- Departamento de Salud del Condado de Prince George **301-883-3525**
- Otros condados **1-800-477-9774**

## Lo que necesita saber acerca del cáncer de mama



## Orientación para las latinas sobre el riesgo y la prevención

Fuentes: American Cancer Society (Cancer.org), National Cancer Institute (Cancer.gov) y National Comprehensive Cancer Network (NCCN.org)

## ¿Cuáles son los factores de riesgo por el estilo de vida o la conducta?

- Consumir bebidas alcohólicas – aumenta el riesgo de cáncer de mama.
- La poca actividad física – las mujeres que hacen ejercicio regularmente tienen un riesgo más bajo.
- El sobrepeso – estar pasada de peso u obesa (IMC>25) aumenta el riesgo.
- No tener hijos o tener el primer hijo después de los 30 años de edad – aumenta el riesgo de tener cáncer de mama.



## ¿Cuáles son los otros factores de riesgo del cáncer de mama?

- El sexo – las mujeres tienen un mayor riesgo de cáncer de mama que los hombres.
- La edad – el riesgo aumenta con la edad.
- Los antecedentes familiares – tener una madre, abuela, hermana o tía con cáncer de mama.
- Los cambios genéticos – los cambios en algunos genes aumentan el riesgo de cáncer de mama.

## ¿Cómo puedo prevenir el cáncer de mama?

Puede disminuir el riesgo de cáncer de mama cambiando los factores de riesgo que usted puede controlar. Por ejemplo:

- **Evite las bebidas alcohólicas** o solo tome 1 bebida por día.
- **Baje de peso** si tiene sobrepeso o es obesa.
- **Haga ejercicio** – intente caminar entre 1¼ y 2½ horas por semana.



## ¿Cómo puedo hacerme una prueba de detección?

Las **pruebas de detección** permiten buscar el cáncer antes de que cause síntomas. La detección temprana del cáncer a menudo facilita su tratamiento. La principal prueba de detección del cáncer de mama se denomina **mamografía** y es una radiografía del seno.

- Si tiene entre 45 y 54 años debe hacerse una mamografía anual.
- Si es menor de 45 años o mayor de 54 debe hablar con su médico acerca de las pruebas de detección.

## Más sobre los factores de riesgo genéticos

En casos raros, el cáncer de mama es un mal de familia. Estas son algunas señales de que el cáncer de mama podría ser un mal de su familia:

- Varios familiares con cáncer de mama, ovario o próstata.
- Usted o un familiar con cáncer de mama, ovario o próstata.
- Un familiar hombre con cáncer de mama.
- Usted o un familiar con cáncer de mama en ambos senos.

## ¿Cuál es mi riesgo de cáncer de mama?

Marque los factores de riesgo suyos para conocer su riesgo de cáncer de mama. Recuerde comentarlos con su médico cuando hable respecto a las pruebas de detección.

- ☐ Soy mujer.
- ☐ Tengo más de 40 años de edad.
- ☐ Tomo más de 1 bebida alcohólica por día.
- ☐ Tengo uno o más de los factores de riesgo genéticos enumerados anteriormente.
- ☐ Tengo sobrepeso o soy obesa.
- ☐ Hago poca actividad física.
- ☐ Tuve mi primer hijo después de los 30 años.

## What is colon cancer?

Colon cancer is a growth that starts in the **colon** (large intestine) that should not be there and can cause health problems. It is related to rectal cancer, which is a growth that starts in the **rectum** (the end of the large intestine). Sometimes these are together called **colorectal** cancer.

## How common is colon cancer?

1 in 23 women will develop colon cancer sometime in her life. Latinos are more likely:

- To be diagnosed with more advanced colon cancer than non-Hispanic whites.

## What causes colon cancer?

There is rarely one cause of cancer. Instead, there are many factors that play a role. These are called **risk factors**. Some risk factors you can change and some you can't.

## Who can I talk to if I'm worried about colon cancer?

You should talk to your doctor if you are worried about your risk of getting colon cancer. Your doctor can:

- Recommend and explain a screening test based on your age and history
- Assess if there is any hereditary risk in your family
- Refer you to a genetic counselor if necessary

### For more information about colon cancer risk and prevention:

- The National Cancer Institute:  
<http://www.cancer.gov/espanol/tipos/colorrectal>
- The American Cancer Society:  
<http://www.cancer.org/espanol/cancer/colonyrecto/guiadetallada/index>

### For free or low cost colon cancer test call:

- Montgomery County Colorectal Cancer screening program **240-777-1222**
- Prince George's County CPEST program **301-883-3525**
- Other counties **1-800-477-9774**

## What you need to know about Colon Cancer



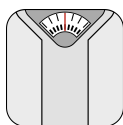
## A Latina's guide to risk and prevention

Sources: The American Cancer Society (Cancer.org), the National Cancer Institute (Cancer.gov), and the National Comprehensive Cancer Network (NCCN.org)



## What are lifestyle or behavior risk factors?

- Diet – eating a lot of red meat (beef, lamb, pork) and processed meat (sausage and lunch meat) raises your risk of colon cancer
- Overweight – being overweight or obese (BMI>25) raises your risk.



- Low physical activity – women who do not do regular exercise have a higher risk.

## What are other colon cancer risk factors?

- Age – risk increases with age.
- Family history – having relatives with colon cancer
- Genetic changes – changes in some genes increase colon cancer risk.
- Type 2 diabetes – having diabetes increases colon cancer risk
- Other colon disease – a history of ulcerative colitis or Crohn's disease

## How can I prevent colon cancer?

You can lower your risk of colon cancer by changing the risk factors that you can control. For example:



- **Change your diet** – avoid red or processed meat and eat more fruits, vegetables, and whole grains.
- **Lose weight** if you are overweight or obese.
- **Exercise** – look for chances to add physical activity to your work or home life.



## How can I get screened?

**Screening** is looking for cancer early before it causes symptoms. Finding cancer early often makes it easier to treat. The most common screening test for colon cancer is a **colonoscopy** and uses a small camera to look inside your colon.

- If you are over age 50, you should have a colonoscopy every 10 years
- If you want to know about other colon cancer screening options, you should talk to your doctor.

## More about Genetic risk factors

In rare cases, colon cancer can run in families. Here are some signs that colon cancer might run in your family:

- Multiple relatives with colon, rectal, or endometrial cancer
- You or a relative with colon, rectal, or endometrial cancer before age 50
- Certain types of colon tumors
- You or a relative with more than 20 colon **polyps** (small growths)

## What is my colon cancer risk?

Check the risk factors you have to see your colon cancer risk. Remember to share them with your doctor when you talk about screening.

- ☐ I am over age 50.
- ☐ I have 1 or more of the genetic risk factors listed above.
- ☐ I am overweight or obese.
- ☐ I eat lots of red meat and few fruits and vegetables.
- ☐ I do little physical activity.
- ☐ I have diabetes or other colon disease.

### ¿Qué es el cáncer de colon?

El cáncer de colon es un crecimiento que comienza en el **colon** (intestino grueso) que no debería estar ahí y que puede causar problemas de salud. Está relacionado con el cáncer de recto, un crecimiento que comienza en el **recto** (al final del intestino grueso). Cuando se presentan juntos, a veces se les denomina cáncer **colorrectal**.

### ¿Qué tan común es el cáncer de colon?

Una de cada 23 mujeres desarrollará cáncer de colon en algún momento de su vida. Es más probable que los latinos:

- Sean diagnosticados con cáncer de colon más avanzado que los blancos no hispanos.

### ¿Qué causa el cáncer de colon?

Pocas veces existe solo una causa del cáncer. Más bien, son muchos los factores que entran en juego. Se les conoce como **factores de riesgo**. Usted puede cambiar algunos factores de riesgo; otros no.

### ¿Con quién puedo hablar si me preocupa el cáncer de colon?

Debe hablar con su médico si le preocupa el riesgo de tener cáncer de colon. Su médico puede:

- Recomendar y explicar una prueba de detección en función de su edad y sus antecedentes.
- Evaluar si hay algún riesgo hereditario en su familia.
- Remitirla a un consejero genético si es necesario.

Para obtener más información sobre el riesgo y la prevención del cáncer de colon:

- The National Cancer Institute:  
<http://www.cancer.gov/espanol/tipos/colorrectal>
- The American Cancer Society:  
<http://www.cancer.org/espanol/cancer>

Para una prueba gratis o económica de cáncer de colon llame al:

- Programa de Detección del Cáncer Colorrectal del Condado de Montgomery **240-777-1222**
- Programa CPEST del Condado de Prince George **301-883-3525**
- Otros condados **1-800-477-9774**

## Lo que necesita saber acerca del cáncer de colon

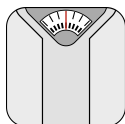


### Una orientación para las latinas sobre el riesgo y la prevención

Fuentes: American Cancer Society (Cancer.org), National Cancer Institute (Cancer.gov) y National Comprehensive Cancer Network (NCCN.org)

## ¿Cuáles son los factores de riesgo por el estilo de vida o la conducta?

- La dieta – comer muchas carnes rojas (res, cordero, cerdo) y procesadas (salchichas y embutidos) aumenta el riesgo de cáncer de colon
- El sobrepeso – estar pasada de peso u obesa (IMC>25) aumenta el riesgo.



- La poca actividad física – las mujeres que no hacen ejercicio regularmente tienen un riesgo más alto.

## ¿Cuáles son los otros factores de riesgo del cáncer de colon?

- La edad – el riesgo aumenta con la edad.
- Los antecedentes familiares – tener familiares con cáncer de colon
- Los cambios genéticos – los cambios en algunos genes aumentan el riesgo de cáncer de colon.
- Diabetes tipo II – tener diabetes aumenta el riesgo de cáncer de colon
- Otra enfermedad de colon – antecedentes de colitis ulcerosa o enfermedad de Crohn

## ¿Cómo puedo prevenir el cáncer de colon?

Puede disminuir el riesgo de cáncer de colon cambiando los factores de riesgo que usted puede controlar. Por ejemplo:



- **Cambie su dieta** – evite las carnes rojas o procesadas y coma más fruta, verdura y granos integrales.
- **Baje de peso** si tiene sobrepeso o es obesa.
- **Haga ejercicio** – busque oportunidades de agregar actividad física a su vida laboral o familiar.



## ¿Cómo puedo hacerme una prueba de detección?

Las **pruebas de detección** permiten buscar el cáncer antes de que cause síntomas. La detección temprana del cáncer a menudo facilita su tratamiento. La prueba de detección más común para el cáncer de colon es una **colonoscopia**, en la que se utiliza una cámara pequeña para observar el interior del colon.

- Si tiene más de 50 años de edad, debe hacerse una colonoscopia cada 10 años
- Si quiere saber acerca de otras opciones de detección del cáncer de colon, debe hablar con su médico.

## Más sobre los factores de riesgo genéticos

En casos raros, el cáncer de colon puede ser un mal de familia. Estas son algunas señales de que el cáncer de colon podría ser un mal de su familia:

- Varios familiares con cáncer de colon, rectal o endometrial
- Usted o un familiar con cáncer de colon, rectal o endometrial antes de los 50 años de edad
- Ciertos tipos de tumores de colon
- Usted o un familiar con más de 20 **pólipos** (pequeños crecimientos) en el colon

## ¿Cuál es mi riesgo de cáncer de colon?

Marque sus factores de riesgo para ver cuál es su riesgo de cáncer de colon. Recuerde comentarlos con su médico cuando hable respecto a las pruebas de detección.

- ☐ Soy mayor de 50 años de edad.
- ☐ Tengo uno o más de los factores de riesgo genéticos enumerados anteriormente.
- ☐ Tengo sobrepeso o soy obesa.
- ☐ Como muchas carnes rojas y poca fruta y verdura.
- ☐ Hago poca actividad física.
- ☐ Tengo diabetes u otra enfermedad del colon.

**APPENDIX E – Complete list of items freelisted by participants**

**Table 7. All breast cancer risk factors freelisted by participants**

<b>Cause or Risk Factor</b>	<b>Participants who freelisted</b>	<b>Frequency</b>	<b>Smith's Salience</b>
Poor diet/eating badly	12	54.55%	0.443
Genes/Genetic Factors	9	40.91%	0.313
Hereditary Factors (Relatives who have had breast cancer)	8	36.36%	0.296
Lack of exercise	7	31.82%	0.160
Hormones/chemicals in food	6	27.27%	0.123
Eating processed food	6	27.27%	0.129
Having a child but not breast-feeding	5	22.73%	0.114
Not have a check-up/mammogram	5	22.73%	0.087
Pollution in the environment	4	18.18%	0.111
Stress	4	18.18%	0.081
Lifestyle	4	18.18%	0.085
Not taking care of oneself	4	18.18%	0.038
A hard hit or blow to the breast	4	18.18%	0.126
Eating food that is not organic	3	13.64%	0.050
Smoking cigarettes or tobacco	3	13.64%	0.056
I don't know	3	13.64%	0.102
Eating red meat	3	13.64%	0.065
Negative or unresolved emotions	3	13.64%	0.108
Chemicals in deodorants	3	13.64%	0.087
Medications	2	9.09%	0.044
Being a woman (female sex)	2	9.09%	0.072
Drinking sugary beverages like soda	2	9.09%	0.077
Food colorings	2	9.09%	0.053
Eating refined sugar	2	9.09%	0.059
Being overweight	2	9.09%	0.041
Hormonal Imbalance	2	9.09%	0.080
Cysts	2	9.09%	0.068
Lack of fruits and vegetables	2	9.09%	0.048
Where food comes from	1	4.55%	0.029
Many carcinogens	1	4.55%	0.025
Oral contraceptives	1	4.55%	0.030
Not having the vitamins that the body needs	1	4.55%	0.039
Using illicit drugs	1	4.55%	0.033
Family environment	1	4.55%	0.027

**Table 7. All breast cancer risk factors freelisted by participants (Cont.)**

<b>Cause or Risk Factor</b>	<b>Participants who freelisted</b>	<b>Frequency</b>	<b>Smith's Salience</b>
Food that doesn't have all the minerals	1	4.55%	0.021
Eating too much salt	1	4.55%	0.018
High fructose corn syrup	1	4.55%	0.015
Splenda	1	4.55%	0.012
Food that isn't natural	1	4.55%	0.009
Fast food	1	4.55%	0.035
The type of milk you drink	1	4.55%	0.020
Psychological reactions to motherhood	1	4.55%	0.015
Breast-feeding	1	4.55%	0.010
Type of bra used	1	4.55%	0.005
Eating many carbohydrates	1	4.55%	0.028
Not having a clean diet	1	4.55%	0.007
Low socioeconomic status	1	4.55%	0.003
Age (older age)	1	4.55%	0.043
Not having biological children	1	4.55%	0.040
Contaminated water	1	4.55%	0.023
Genetically modified food	1	4.55%	0.020
Sedentary lifestyle	1	4.55%	0.009
Not sleeping well	1	4.55%	0.006
Antibiotics	1	4.55%	0.030
Free radicals	1	4.55%	0.004
Daily life	1	4.55%	0.041
Health habits	1	4.55%	0.036
Eating junk food	1	4.55%	0.018
Not preparing food at home	1	4.55%	0.014
Not washing one's armpits	1	4.55%	0.045
Sweat	1	4.55%	0.023
Cellular changes	1	4.55%	0.011
High-fat diet	1	4.55%	0.030
Inflamed lymph nodes	1	4.55%	0.015
Spending too much time in the heat	1	4.55%	0.027
The pressure of a mammogram	1	4.55%	0.009
Drinking a lot of coffee	1	4.55%	0.045
Race	1	4.55%	0.009
Weakened immune system	1	4.55%	0.034
Not eating much	1	4.55%	0.011
Not removing breast milk	1	4.55%	0.036
Using tight bras	1	4.55%	0.009

**Table 8. All colon cancer risk factors freelisted by participants**

<b>Cause or Risk Factor</b>	<b>Participants who freelisted</b>	<b>Frequency</b>	<b>Smith's Salience</b>
Poor diet	12	54.55%	0.481
High-fat diet	7	31.82%	0.188
Genes/Genetic Factors	6	27.27%	0.186
Lack of medical care	6	27.27%	0.112
Pollution in the environment	5	22.73%	0.122
Hereditary Factors (Relatives who have had colon cancer)	5	22.73%	0.149
Eating Junk Food	5	22.73%	0.126
Eating processed food	4	18.18%	0.137
Constipation	4	18.18%	0.140
Hormones/chemicals in food	3	13.64%	0.093
Negative or unresolved emotions	3	13.64%	0.044
Stress	3	13.64%	0.040
Colitis	3	13.64%	0.061
Dairy products	3	13.64%	0.032
Lack of exercise	3	13.64%	0.066
An infection in the colon	3	13.64%	0.078
Another primary cancer	2	9.09%	0.047
Drinking sugary beverages like soda	2	9.09%	0.064
Drinking a lot of alcohol	2	9.09%	0.086
Caffeine	2	9.09%	0.056
Spicy food	2	9.09%	0.057
Eating red meat	2	9.09%	0.051
Not eating nutritious food	2	9.09%	0.025
Fast Food	2	9.09%	0.022
Hemorrhoids	2	9.09%	0.082
Not drinking enough water	2	9.09%	0.034
Lack of fiber	2	9.09%	0.060
Sodium nitrate	1	4.55%	0.039
Radiation	1	4.55%	0.026
Cellular changes	1	4.55%	0.006
Over-eating	1	4.55%	0.045
Way of bathing	1	4.55%	0.026
Being a nervous person	1	4.55%	0.013
Not having a clean colon	1	4.55%	0.045
HPV	1	4.55%	0.045
Eating non-nutritious food	1	4.55%	0.030

**Table 8. All colon cancer risk factors freelisted by participants (Cont.)**

<b>Cause or Risk Factor</b>	<b>Participants who freelisted</b>	<b>Frequency</b>	<b>Smith's Salience</b>
White flour	1	4.55%	0.035
Excesses	1	4.55%	0.025
Being a man (male sex)	1	4.55%	0.005
Exposure to chemicals	1	4.55%	0.009
Food colorings	1	4.55%	0.039
Chemicals in lotions	1	4.55%	0.026
Synthetic ingredients in deodorants	1	4.55%	0.019
Free radicals	1	4.55%	0.013
Having a stressed stomach	1	4.55%	0.045
Smoking cigarettes or tobacco	1	4.55%	0.039
Irritated colon	1	4.55%	0.045
Toxins	1	4.55%	0.043
A rupture in the colon	1	4.55%	0.040
General poor digestion	1	4.55%	0.034
Not eating	1	4.55%	0.026
A stomach ulcer	1	4.55%	0.011
Hamburgers	1	4.55%	0.023
French Fries	1	4.55%	0.019
Eating late at night	1	4.55%	0.011
Using illicit drugs	1	4.55%	0.008
Taking a lot of medications	1	4.55%	0.004
Lifestyle	1	4.55%	0.023
Bad habits	1	4.55%	0.008
Canned foods	1	4.55%	0.025
Spending a lot of time sitting	1	4.55%	0.015
Microwaved food	1	4.55%	0.010
Cell phones	1	4.55%	0.005
Pork	1	4.55%	0.008
Nothing	1	4.55%	0.045
Self-medicating	1	4.55%	0.028
Using a lot of seasonings	1	4.55%	0.017
Too much salt	1	4.55%	0.011
Corn	1	4.55%	0.045
Things the system can't digest well	1	4.55%	0.032
Metal scraping the colon	1	4.55%	0.027
Not knowing one's body	1	4.55%	0.009
Obesity	1	4.55%	0.005

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## Curriculum Vitae

Katherine Elizabeth Fiallos

Born: October 18, 1986 Columbia, Maryland

### Education

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<b>Johns Hopkins University – Baltimore, MD</b>	<b>9/2014 – 2/2017</b>
<b>National Human Genome Research Institute – Bethesda, MD</b>	
ScM Candidate, Genetic Counseling Training Program	
<b>Kalamazoo College – Kalamazoo, MI</b>	<b>9/2004 – 6/2008</b>
BA in Spanish Language and Literature/International and Area Studies	
<i>Summa Cum Laude</i>	
<b>Universidad San Francisco de Quito – Quito, Ecuador</b>	<b>9/2006 – 5/2007</b>
Year abroad, liberal arts study with classes taught in Spanish	

### Genetic Counseling Training Experience

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#### ONCOLOGY

<b>National Cancer Institute – Bethesda, MD</b>	<b>Fall 2016</b>
Specialty: Li-Fraumeni research study and ClinOmics research study.	
<b>Walter Reed, John P. Murtha Cancer Center – Bethesda, MD</b>	<b>Spring 2016</b>
Specialty: hereditary cancer syndromes	
<b>Universidad de Desarrollo/Clínica Alemana – Santiago, Chile</b>	<b>Summer 2015</b>
Specialty: hereditary cancer syndromes, sessions in Spanish	

#### PEDIATRICS

<b>Hospital Padre Hurtado – Santiago, Chile</b>	<b>Summer 2015</b>
Specialty: pediatric genetics, sessions in Spanish	
<b>Johns Hopkins Hospital – Baltimore, MD</b>	<b>Fall 2015</b>
Specialty: general genetics, neurology, muscular dystrophy, connective tissue disorders, skeletal dysplasias	

#### PRENATAL

<b>Walter Reed, MFM Clinic – Bethesda, MD</b>	<b>Spring 2015</b>
Specialty: high-risk pregnancy	
<b>Howard County General, MFM Clinic – Columbia, MD</b>	<b>Fall 2014</b>
Specialty: prenatal genetics	

#### CARDIOLOGY

<b>Johns Hopkins Hospital – Baltimore, MD</b>	<b>Fall 2016</b>
Specialty: inherited heart conditions	

#### LABORATORY

<b>GeneDx – Gaithersburg, MD</b>	<b>Winter 2015</b>
Specialty: clinical genetic testing	

### Additional Relevant Experience

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<b>USA Science &amp; Engineering Festival</b>	<b>4/2016</b>
Position: Volunteer	
Role: Conducted trait tree exercise with children and families	
<b>ConnectUS – Livonia, MI</b>	<b>1/2014 – 8/2014</b>
Position: Volunteer Coordinator and Administrative Assistant	
Role: General office duties and recruitment of volunteers to assist in project workshops for adults with severe multiple disabilities	
<b>Fundación General Ecuatoriana – Quito, Ecuador</b>	<b>1/2007 – 5/2007</b>
Position: Volunteer	
Role: Assisted with career training for developmentally disabled youth	

## **Research and Presentations**

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### ***Where Culture Meets Genetics: Exploring Latinas' Causal Attributions of Breast and Colon Cancer and Mental Models of Disease Inheritance***

- National Institutes of Health, NHGRI – Bethesda, MD
- Purpose: To identify and describe a common cultural model of causal attributions of breast and colon cancer and explore disease inheritance among Latina immigrants
- Design: Semi-structured, qualitative interviews and cultural consensus analysis
- Key Results: No presence of a cultural consensus model of risk factors for breast and colon cancer, emphasis on genetics as a risk factor for both cancers, similar causal attributions and models of disease inheritance as other populations.
- Original Master's Thesis submitted January 2017

### ***Genetic counselor consent reduces ancestry-related differences in choice to receive secondary findings in a large-scale genomic sequencing study***

- Johns Hopkins University – Baltimore, MD
- Purpose: To identify variation in participant choices regarding return of secondary findings
- Design: Retrospective, observational data analysis
- Key Results: Participants of non-European ancestry were less likely to choose to receive secondary findings when their consent process was conducted by a physician
- Poster presented at the National Society of Genetic Counselors Annual Education Conference September, 2016
- In press at the European Journal of Human Genetics January 2017

### ***Prenatal Skeletal Dysplasias***

- GeneDx – Gaithersburg, MD
- Purpose: To review the literature on genes related to prenatal skeletal dysplasias for inclusion on a new panel test
- Design: Literature review
- Key Results: Summary of the literature on the most common prenatal skeletal dysplasias
- Presented to GeneDx employees for continuing education credit March 2015
- Genetic test information sheet posted on GeneDx website:  
<http://www.genedx.com/wp-content/uploads/2016/02/Prenatal-Skeletal-Dysplasias-Info-Sheet.pdf>

### ***Genotypic Diversity in an Alu Element of the LDLR Gene***

- Eastern Michigan University – Ypsilanti, MI
- Purpose: To develop an assay, which can be used to indicate ethnic origin and paternity based on genotypic differences
- Design: PCR and enzyme digestion.
- Key Results: Variation in cut sites of certain enzymes by ethnicity
- Poster presented at the Eastern Michigan University Undergraduate Symposium March, 2014

## **Honors and Awards**

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Phi Beta Kappa member

2008

Alpha Lambda Delta member

2005